

Wright State University

CORE Scholar

---

[Browse all Theses and Dissertations](#)

[Theses and Dissertations](#)

---

2013

## Disability Identity Formation in People with Severe Mental Illness and Treatment Seeking and Compliance: A Participatory Action Research Study

Kimberly M. Sommers  
*Wright State University*

Follow this and additional works at: [https://corescholar.libraries.wright.edu/etd\\_all](https://corescholar.libraries.wright.edu/etd_all)



Part of the [Psychology Commons](#)

---

### Repository Citation

Sommers, Kimberly M., "Disability Identity Formation in People with Severe Mental Illness and Treatment Seeking and Compliance: A Participatory Action Research Study" (2013). *Browse all Theses and Dissertations*. 767.

[https://corescholar.libraries.wright.edu/etd\\_all/767](https://corescholar.libraries.wright.edu/etd_all/767)

This Dissertation is brought to you for free and open access by the Theses and Dissertations at CORE Scholar. It has been accepted for inclusion in Browse all Theses and Dissertations by an authorized administrator of CORE Scholar. For more information, please contact [library-corescholar@wright.edu](mailto:library-corescholar@wright.edu).

**DISABILITY IDENTITY FORMATION IN PEOPLE WITH SEVERE MENTAL  
ILLNESS AND TREATMENT SEEKING AND COMPLIANCE: A  
PARTICIPATORY ACTION RESEARCH STUDY**

**PROFESSIONAL DISSERTATION  
SUBMITTED TO THE FACULTY  
OF  
THE SCHOOL OF PROFESSIONAL PSYCHOLOGY  
WRIGHT STATE UNIVERSITY**

**BY**

**KIMBERLY MICHELLE SOMMERS, Psy.M.**

**IN PARTIAL FULFILLMENT OF THE  
REQUIREMENTS FOR THE DEGREE  
OF  
DOCTOR OF PSYCHOLOGY**

**Dayton, Ohio**

**August, 2014**

**COMMITTEE CHAIR: Julie Williams, Psy.D., ABPP**

**Committee Member: Michelle Schultz, Psy.D.**

**Committee Member: Irma Johnston, Psy.D.**

Copyright by  
Kimberly Michelle Sommers  
2013

**WRIGHT STATE UNIVERSITY**  
**SCHOOL OF PROFESSIONAL PSYCHOLOGY**

July 1, 2013

I HEREBY RECOMMEND THAT THE DISSERTATION PREPARED UNDER MY SUPERVISION BY **KIMBERLY MICHELLE SOMMERS** ENTITLED **DISABILITY IDENTITY FORMATION IN PEOPLE WITH SEVERE MENTAL ILLNESS AND TREATMENT SEEKING AND COMPLIANCE: A PARTICIPATORY ACTION RESEARCH STUDY** BE ACCEPTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PSYCHOLOGY.

---

Julie Williams, Psy.D. ABPP  
Dissertation Director

---

La Pearl Logan Winfrey, Ph.D.  
Associate Dean

## **Abstract**

The study of facilitators of treatment seeking and compliance in people with severe mental illness represents a significant gap in the current literature. The present study, using a Participatory Action Research (PAR) approach, attempted to identify facilitators to treatment seeking and compliance through the lived experiences of people living with severe mental illness. Interviews were used to gather information about the experience of people with severe mental illness regarding disability identity development, recovery, interactions with treatment and treatment providers, the experience of being diagnosed with a severe mental illness, and the impact of psychiatric disability on family, friends, and functioning. Results reflected the importance of religion and spirituality, trust, coping and self-care, disability identity, and social and family support as key facilitators to treatment seeking and compliance in people with severe mental illness. Implications for the provision of services to people with severe mental illness and for future research are discussed.

## Table of Contents

<b>CHAPTER 1 .....</b>	<b>1</b>
Statement of the Problem.....	1
Aim and Purpose.....	2
<b>CHAPTER 2: Literature Review .....</b>	<b>4</b>
Severe Mental Illness.....	4
Societal Understanding of Severe Mental Illness .....	5
Models of Disability .....	5
Morality Model .....	6
Medical Model.....	6
Social Minority Model.....	8
Impact of Society View of Severe Mental Illness .....	11
Treatment of Severe Mental Illness .....	13
Evidence-Based Practices .....	14
Treatment Seeking .....	16
Recovery and Outcomes .....	18
Disability Identity Development Models.....	21
Models of Disability Identity Development .....	22
Integration Model.....	22
Severe Mental Illness Integration Model.....	23
Internalized Ableism and Shame .....	26
Schizophrenics Anonymous.....	28
Conclusion .....	30

<b>CHAPTER 3: Method .....</b>	<b>32</b>
Qualitative Research .....	32
Participatory Action Research .....	32
Participants.....	34
Materials .....	35
Procedure .....	36
<b>CHAPTER 4: Results .....</b>	<b>38</b>
Demographics .....	38
Diagnostic Variables of the Participants.....	39
Interview Responses .....	41
Question One .....	41
Question Two.....	43
Question Three.....	44
Question Four.....	46
Question Five .....	48
Question Six.....	49
Question Seven .....	51
Question Eight .....	52
Interview Themes.....	54
Models of Disability .....	54
Morality Model .....	54
Medical Model .....	54
Social Minority Model.....	55

Severe Mental Illness Integration Model .....	56
Recovery .....	57
Treatment .....	57
Medication .....	57
Medication Compliance .....	58
Control of Medication and Treatment.....	59
Coping and Self-Care.....	59
Schizophrenics Anonymous.....	60
Religion and Spirituality .....	61
Suicide.....	61
Step Seven: I Choose To Live .....	62
Work, Career, and Education.....	62
<b>CHAPTER 5: Discussion and Conclusions .....</b>	<b>64</b>
Demographics .....	64
Models of Disability .....	66
Morality Model .....	67
Medical Model .....	68
Social Minority Model.....	71
Severe Mental Illness Integration Model.....	72
Identity Development and Facilitators of Treatment .....	73
Recovery .....	74
Personal Definitions of Recovery .....	75
Religion and Spirituality .....	76



Sources of Social Support.....	78
Social Network.....	78
Family Support .....	80
Schizophrenics Anonymous.....	82
Trust .....	84
Communication with Treatment Providers .....	84
Coping and Self-Care.....	86
Work, Career, and Education.....	86
Limitations and Implications for Future Research.....	87
Relationship of Primary Researcher With S.A. Group .....	89
Interviews.....	89
<b>CHAPTER 6: Summary .....</b>	<b>91</b>
Appendix A: Interview Questions .....	93
Appendix B: Interview Protocol .....	94
Appendix C: Consent Form .....	95
Appendix D: Schizophrenics Anonymous Recruitment Letter .....	97
Appendix E: Demographics Form .....	98
Appendix F: Interview Transcriptions .....	99
References.....	167

## **List Of Tables**

Table 1: Demographics of Participants.....	38
Table 2: Additional Demographics of Participants.....	39
Table 3: Diagnostic Variables of the Participants.....	40

## **CHAPTER 1**

### **Statement of the Problem**

In 2001, the latest year for which data is available, the prevalence of the psychiatric disability of severe mental illness in the United States was estimated at 15 million adults (National Household Survey on Drug Abuse [NHSDA], 2002). To date, the treatment for severe mental illness has largely focused on elimination of symptoms while ignoring other quality of life variables, such as disability identity. While treatment seeking and compliance has been consistently addressed in the literature, facilitating variables have received less attention than barriers (Gulliver, Griffiths, & Christensen, 2010). The following dissertation proposal addresses how disability identity for individuals with severe mental illness facilitates treatment seeking and compliance. Bassman (2001) stated, “once diagnosed and treated for a ‘major mental illness,’ your life’s course is deeply affected by how you integrate that experience into your identity” (p. 18). Severe mental illness is disruptive to a person’s sense of self (Wisdom, Bruce, Saedi, Weis, & Green, 2008; Inder et al., 2008).

Onken and Slaten (2000) developed a framework for understanding disability identity formation in people diagnosed with severe mental illness. However, the link between disability identity formation and its impact on treatment seeking and compliance in people with severe mental illness was left unexplored. Yanos, Roe, and Lysaker (2010) found that the impact of a psychiatric disorder is mediated by its attached meanings. Moreover, a person diagnosed with severe mental illness that accepts the

socially constructed assumptions that mental illness means incompetence and inadequacy will have poorer treatment outcomes. These negative assumptions about severe mental illness are internalized socially constructed ableistic messages that lead to shame and fear and impact outcomes. The same authors briefly mention that attaching positive meanings to a diagnosis of severe mental illness might have a positive impact on treatment outcomes but provided no support for that hypothesis.

Further, a review of the literature shows while treatment seeking and compliance are important, there are gaps around the identification of facilitators for treatment seeking and compliance in people diagnosed with severe mental illness (Gulliver et al., 2010). Success or failure of recovery with a diagnosis of severe mental illness has traditionally depended on psychopharmacological medications, psychiatric hospitalizations, and community mental health and social benefit support systems (Kreyenbuhl, Buchanan, Dickerson, & Dixon, 2010). Recovery has traditionally been measured by the absence of symptoms as dictated by a medical model while ignoring quality of life for people diagnosed with severe mental illness (Davidson, 2010). However, consumer-driven movements have challenged this system and definition of recovery. This challenge has created a divide between empirically supported treatments, clinical understanding of severe mental illness, and the lived experience of those with severe mental illness (National Alliance on Mental Illness [NAMI], n.d.). This study aims to learn from the lived experiences of people diagnosed with severe mental illness, using a participatory action research (PAR) approach, to develop an understanding of how the development of disability identity is a facilitator for treatment seeking and compliance.

## **Aim and Purpose**

The aim of this study is to develop a framework to begin to understand how disability identity around the diagnosis of severe mental illness can impact treatment, with particular focus on variables that facilitate treatment seeking and compliance. This has been accomplished through a PAR method consisting of interviews with individuals diagnosed with severe mental illness. Limited research has been done through interviews with individuals diagnosed with severe mental illness (Magliano, Fiorillo, Malangone, Del Vecchio, & Maj, 2008). The approach hears from those impacted by severe mental illness and provides this community and treating clinicians with strategies through which to gather evidence to identify disability identity formation as a facilitator to treatment seeking and compliance in people diagnosed with severe mental illness. This study provides information about what kind of questions should be asked of people with severe mental illness pertaining to identity formation and recovery in promoting treatment seeking and compliance.

## **CHAPTER 2**

### **Literature Review**

The following literature review will have several purposes. First, it will define and identify the prevalence of severe mental illness. Secondly, it will outline the history of disability as related to psychiatric disability and explore how views of disability have impacted treatment, recovery, and outcomes for people diagnosed with severe mental illness. Finally, the relationship between disability identity formation and internalized ableism will be explored.

#### **Severe Mental Illness**

Severe mental illness applies to mental disorders that interfere with some area of social functioning (U.S. Department of Health and Human Services [USDHHS], 1999). The NHSDA (2002) defines severe mental illness as a mental, behavioral, or emotional disorder that is diagnosable currently or within the past year according to *DSM-IV-TR* criteria, and results in serious functional impairment. This category includes schizophrenia, bipolar disorder, severe forms of depression, panic disorder, and obsessive-compulsive disorder. The cost of severe mental illness, both direct (expenditures for mental health services and treatment) and indirect (expenditures and losses related to disability) was estimated at an annual cost of \$317.6 billion for the year 2002 (National Institute of Mental Health [NIMH], 2010, July 29). The personal costs for those diagnosed with severe mental illness, and for their families, friends, and communities are significant and include rejection, lack of support, and isolation. In 2001,

approximately 15 million adults were estimated to have a diagnosis of a severe mental illness and only about half of these adults received any type of treatment in the previous year (NHSDA, 2002).

This study will focus on schizophrenia and schizoaffective disorder as the primary diagnoses that define severe mental illness. These disorders are among the costliest and most functionally disruptive disorders (NHSDA, 2002; American Psychiatric Association [*DSM-IV-TR*], 2000). Schizophrenia and schizophrenia-spectrum disorders are marked by the presence of negative symptoms (flattened affect, alogia, avolition, anhedonia) and positive symptoms (delusions, hallucinations, disorganized speech, grossly disorganized or catatonic behavior) (*DSM-IV-TR*, 2000). Each disorder is differentiated based on symptom presentation and duration of symptoms. The prevalence of schizophrenia is in the range of 0.5 to 1.5 percent in adults with an annual incidence of 0.5 to 5.0 per 10,000 people. There are 27 different symptom profiles of people diagnosed with schizophrenia using *DSM-IV-TR* criteria (McGuire, 2000).

The course of schizophrenia and schizoaffective disorder is variable, some people diagnosed with these disorders go through cycles of increased symptoms and remission and others remain chronically ill. Complete remission is uncommon according to the *DSM-IV-TR* (2000). Traditional concepts of schizophrenia note that only 10-20 percent of people diagnosed with schizophrenia recover, as defined by the complete elimination of symptoms. However, the recovery movement has challenged the traditional definition of recovery to include the possibility of living with continued symptoms and improving role functioning socially and in work. By expanding the definition of recovery, longitudinal data suggests that up to 68 percent of people recover or experience

significant improvement in symptoms and functioning (McGuire, 2000). Cross-cultural research has found recovery rates of at least 45 and up to 65 percent in countries outside of the United States (Davidson, 2010). The age of onset impacts the course of the illness (*DSM-IV-TR*, 2000). Those who experience earlier onset in the early to mid-20s, often men, have poorer adjustment and typically worse outcomes. Those, whose illness manifests in their late 20s, typically women, are associated with less cognitive impairment and better outcomes.

**Societal understanding severe mental illness.** Mental illness has been stigmatized throughout history. In the 18<sup>th</sup> century, wealthy British families sought private confinement for family members with mental illness to hide them away so not to dishonor the family by their behavior (Braddock & Parish, 2001). This practice was part of the institutionalization movement that led to the establishment of hospitals, like Bethlehem Hospital in the Pennsylvania colony to remove “Lunaticks of Persons distempered in Mind and deprived of their rational Faculties” (p. 16) from colonial American towns. Historical understandings of mental illness are depicted in disability studies literature through an understanding of three major models of disability. Exploring the historical construction of disability and of mental illness as a disability helps to understand the development of overt and covert beliefs held by society, which have then informed mental health professionals, and impacted the individuals who have been diagnosed with severe mental illness and their families.

**Models of disability.** Historical models of disability have significant impacts on the ways society continues to think about and construct disability. The three major models of disability will be discussed.



***Morality model.*** The oldest model of disability and mental illness is the moral model wherein mental illness and disability are understood as a defect caused by a moral lapse or sins, as a failure or test of faith, and as evil (Olkin, 2002). Consequently, individual with psychiatric disabilities were believed to have been possessed by devils and spirits. Interventions would likely involve prayer or an exorcise. Other interventions could be dangerous, such as trepanning, a method in which a burr hole was drilled in a person's skull to allow spirits to escape (Mackelprang & Salsgiver, 1996). In some cultures, people diagnosed with a mental illness were viewed as shamans or people sharing a special connection with god (Olkin, 2002).

Plato, whose thought is the basis of much western philosophy, saw people with disabilities as standing in the way of a perfect world (Mackelprang & Salsgiver, 1996). This model invoked a sense of shame associated with disability. As a result, people with disabilities were shamed, ostracized and hidden. This is still the most widely held view of disability in the world as evidenced by the secrecy of mental illness and the social construction of shame that surrounds disability (NAMI, n.d.).

***Medical model.*** The paradigm of morality and spiritual understandings of disability transformed to a pathology-based view of illness with the advent of the modernization of medicine and is referred to as the medical model (Bassman, 2000). This model emerged in the mid-1800s and is the most widespread model of disability in Western cultures (Olkin, 2002). While the etiology of severe mental illness is not understood entirely, the medical model views disability as a defect or failure of a bodily system that leads to abnormality and pathology. Therefore, this model assumes that a defect or abnormality must be cured so that the individual can function normally within

society. Treatment, therefore, is directed towards the elimination of symptoms. The problem lies within the person and a cure must be found.

Given that the medical model views mental illness as a fixable problem, treatment providers as defined by training in medicine and science are the experts in charge of treatment (Olkin, 2002). Treatment becomes for the person with a disability, and is not directed by the person being treated. This can create a system of paternalism and charity towards those with disabilities. Treatment of people diagnosed with a severe mental illness can become paternalistic due to the assumed impairments in cognitive functioning and the demonstrations of bizarre and disorganized behavior (Bassman, 2000).

Treatment within this model for severe mental illness is focused on psychopharmacological medications. Even non-medical clinicians defer to drug treatment when confronted with treating a person diagnosed with a severe mental illness (Bassman, 2005). These medications can have a powerful impact by reducing symptomatology, but can also have serious side effects. Since these medications are seen as the cure in the medical model, there is a history of forcing treatment on people with a mental illness who are assumed to be incapable of making informed decisions about their own care (Bassman, 2000).

There is no cure for schizophrenia (Davidson, 2010). Still, the medical field and the NIMH continue to seek new psychopharmacological interventions while new methods of psychosocial interventions receive little attention and financial funding (Bassman, 2005). Since there is no cure, the person diagnosed with severe mental illness remains “sick” even if he or she is functioning well with the psychiatric disability. The continued search for and faith in finding a cure for schizophrenia and other severe mental

illness has a negative impact on ideas of identity development surrounding the psychiatric disability. Given the belief that the disability will be cured, there is no need to develop a disability identity. Therefore, medical model interventions exclude disability identity formation as part of recovery and treatment.

The language of the medical model is reflected in current understandings of mental illness. For example, the National Institute of Mental Health (NIMH) defines schizophrenia as a disorder of brain circuits. Associated research focuses on identifying specific genes and exploring the cognitive deficits of schizophrenia that may precede the presentation of positive symptoms (Insel, 2010, November 10). This research is focused on scientifically explaining the disorder with little attention paid to the lived experience of the diagnosis. The medical model purports to be a path for decreasing stigma against disability and mental illness, however, discrimination against people diagnosed with severe mental illness continues because this population is believed to be unable to control the cause of their disability (Bassman, 2001). The medical model victimizes the person with a diagnosis of mental illness by making him or her a victim of a brain disease, therefore, presenting that person as an object of pity, at best. Martin, Pescosolido, and Tuch (2000) found that people prefer greater social distance from those with mental illness even when there is an understanding of the medical model approach to defining the illness.

***Social minority model.*** The disability rights movement developed as a part of the civil rights movements of the 1960s and 1970s and in response to ableism. Ableism is the set of assumptions and practices that systematically promote negative physical, mental, or behavioral differences that are then labeled as disabilities (Onken & Slaten,

2000). As people began to form disability communities, new ways of conceptualizing disability arose and disability became a social justice issue (Gill, 1997; Pledger, 2003). This new model of disability is the social minority model that defines disability as a social construct, not as personal pathology. In social minority model, disability stems from institutionally based oppression of a minority population in a social environment that fails to account for individual differences (Landsman, 2005; Olkin, 2002). Disability is defined by how the person is able to function within the environment and how these external factors contribute to and shape the experience of disability. Therefore, the social minority model promotes integration of disability into a sense of self and rejection of shame associated with the internalization of ableism instead of viewing the elimination of symptoms or disorder as the only goal.

Proponents of the social minority model work toward political, economic, and social changes to increase access, inclusion, and awareness (Olkin, 2002). By placing the construction of the disability outside of the individual, the social minority model works towards depathologizing disability and increasing a sense of community and pride. Increased community and pride has led to social justice campaigns like the consumer/survivor/ex-patient movement that has become active in working towards public policy and medical treatment changes (Bassman, 1997). This is a social justice movement that works to eliminate the medical model approach to treatment wherein the medical professionals are in charge and the goal is symptom elimination. Treatment within a social minority model would recognize the lived experience of severe mental illness.

Severe mental illness is frequently a cyclical pattern of increasing symptoms and remission (Lysaker & Buck, 2008). The systems of social and financial support currently in place in the United States does not recognize that people diagnosed with severe mental illness have different needs at different points in the course of the illness. The systems of social benefits of Social Security, Medicare/Medicaid, Bureau of Vocational Rehabilitation and welfare are constructed through the medical model. Those systems view recovery as linear and time-specific. This ignores the cycle of mental illness and works to keep people “sick” so they can continue to receive needed benefits (Mackelprang & Salsgiver, 1996). Employers do not recognize mental illness as a disability to be accommodated. People with mental illness are frequently denied access to employment and are kept as a segregated social minority. The social minority movement calls for a change to these systems and works towards greater inclusion and increased access to employment and independent living.

While the social minority model purports to promote inclusiveness, it has largely ignored the presence of severe mental illness or psychiatric disability within the disability rights movement, suggesting pervasive exclusion of those with psychiatric disabilities and internalization of oppressive beliefs of shame, fear, and avoidance even within the disability community. The disability community may avoid psychiatric disabilities out of a fear of stigma contagion (Gill, 1997). This is painfully evidenced by the fact that many of the ground-breaking political, social and economic changes advocated for and won by the social minority movement have had little impact on the status and functioning of those with psychiatric disabilities.

**Impact on societal view of severe mental illness.** These different models of disability have created attitudinal scripts and related behavior that impact public perception of severe mental illness. Public perception continues to share the pathologizing and fear-based views of the moral and medical models of disability. This moral model perpetuates the myth of the link between severe mental illness and violence that leads to increased discrimination and stigma (Substance Abuse & Mental Health Services Administration [SAMHSA], 2008, September 24). Models of disability and understanding of severe mental illness have changed, but the larger societal view of severe mental illness continues to be fearful and avoidant.

The news and entertainment media promotes the link between violence and severe mental illness (SAMHSA, 2008, September 24). More than a third of news media stories about mental illness focus on dangerousness, while the remaining portion focus on medical interventions or on other negative characteristics associated with mental illness, such as, unpredictability and unsociability. The perceived degree of dangerousness that is ascribed to people with mental illness leads to an increased stigmatization and ostracism of this population (Martin et al., 2000). Even as there is an increased public acceptance of the medical model of mental illness, perceived dangerousness and social distance have not decreased (Pescosolido et al., 2010). Neff (1995) wrote from personal experience as a person with severe mental illness and stated that she has seen others react to her when she goes out in public dressed as a “bag lady”. She reported that people react with ridicule, disgust, and fear. This social distance has an impact on the health of people with severe mental illness (Botha, et al., 2010). People with severe mental illness with

poor support networks and challenging social environments are likely to remain well for shorter periods of time.

People diagnosed with severe mental illness have internalized messages about dangerousness, as a part of internalized ableism, before any signs of severe mental illness are experienced personally. This continues to impact self-perceptions through internalized messages of ableism following the diagnosis of severe mental illness (Yanos et al., 2010). These internalized messages promote the false, but popular, idea that people with mental illness are dangerous, uncontrolled, and unpredictable (Appleby, Mortensen, Dunn, & Hiroeh, 2001). These same authors found that people diagnosed with severe mental illness and other psychiatric disabilities are far more likely to be victims than perpetrators of violent crime. When compared to the risk for violence associated with the combination of other demographic variables including being male gender, young age and within a lower socioeconomic status, the risk for violence associated with mental illness is significantly lower (SAMHSA, 2008, September 24). Despite evidence against the association of violence and severe mental illness, the public and private perception of violence and fear persist towards people diagnosed with severe mental illness.

The shame of mental illness is marked by the silence that surrounds it (Onken & Slaten, 2000). It is a hidden disability that people keep secret and only tell trusted others. It is different from medical illnesses caused by bacteria or tumors because the sympathy often evaporates (Smart Ass Cripple, 2011, February 28). Smart Ass Cripple, an online diarist with muscular dystrophy, described an interaction with one of his personal assistants, Chris, who stated, “when you’re mentally ill, people think you should just

suffer in a room of needles and pins. You deserve it” (Smart Ass Cripple, 2011, February 28). Chris spoke out because he felt no shame related to being mentally ill, but he described a process of working through the shame related to internalized stigma and ableism. In contrast, Neff (1995) stated that the shame and hurt feelings that belong to her as a person with mental illness “never seem to wear off” (p. 338).

### **Treatment of Severe Mental Illness**

These models of disability impact and inform treatment. Therefore, the treatment of severe mental illness has changed over time to reflect developments in science, medicine and conceptualizations of disability. Treatments stemming from the moral model focused on spiritual interventions, and many people diagnosed with severe mental illness, continue to turn to prayer for support in their recovery (Olkin, 2002). In some cultures, shamanism is still used for intervention, and severe mental illness is sometimes seen as a link between this world and a spiritual one.

The predominant paradigm for treating people with severe mental illness is the medical model. Psychopharmacological medications are often the first step in treating people diagnosed with severe mental illness, and they can be effective in reducing symptoms and helping people better manage with the diagnosis of severe mental illness (Gelman, 1999). Bassman (2000) described painful medical interventions that were used in his own treatment when he was initially diagnosed with schizophrenia. He underwent 40 insulin coma treatments and electroconvulsive shock treatments to treat his schizophrenia in the hospital. He stated that these treatments made him dull and rendered his behavior acceptable to the doctors monitoring his progress but did not help him.



The first antipsychotic medications were a miracle for the treatment of severe mental illness (Gelman, 1999). Proponents of the medical model and social minority views of disability see medications as an important part of recovery (Bassman, 2001). Effective medications are an important aspect of recovery from severe mental illness, but many people struggle with side effects and the negative and dependent messages attached to taking antipsychotic medications (Spaniol, Gagne, & Koehler, 1999). Advancements in medications decreased adverse side effects and increased knowledge of the brain chemistry behind schizophrenia and other severe mental illnesses. These medications are effective for a large proportion of individuals with severe mental illness, and the medical model still guides much of the research into new treatment interventions. Money is therefore not directed towards new potentially effective psychosocial interventions (Davidson, 2010).

**Evidence-based practices.** The research being conducted on psychosocial interventions for schizophrenia and schizoaffective disorder focuses on identifying evidence-based practices (Kreyenbuhl et al., 2010). Efficacious evidence-based psychosocial treatments for schizophrenia share several common elements (Fenton & Schooler, 2000). These treatments do not claim to be for everyone and can be modified to account for individual differences. These treatments require a foundation of trust and rapport between treatment providers and client. They use all levels of support including the client's family, and they seek to empower the client by placing self-defined goals at the center of treatment. As part of the medical model, evidence-based treatments use a stress-vulnerability-coping illness and recovery model.

The Schizophrenia Patient Outcomes Research Team (PORT) project identifies evidence-based practices for the treatment of schizophrenia (Kreyenbuhl et al., 2010). Over 600 studies were evaluated to determine best practices for the treatment of schizophrenia, and PORT ultimately recommended 16 psychopharmacologic and eight psychosocial treatments. Psychopharmacologic treatments focused on the use of medications to manage symptoms and side effects of other medications. The outcomes of these interventions are evaluated in terms of the presence or reduction of symptomatology. Psychosocial interventions work to support the person in his or her environment. Psychotherapeutic interventions were found effective in PORT based on how well these interventions provided emotional support, enhanced functional recovery, and altered the underlying illness process (Dickerson & Lehman, 2011). These interventions are recommended based on how the target behavior is met or reduced (Kreyenbuhl et al., 2010).

Several of the psychosocial interventions recommended by PORT were focused on maintaining people diagnosed with schizophrenia in the community. Assertive Community Treatment (ACT) is a community-based care model that involves comprehensive services to reduce hospitalizations and homelessness among individuals with schizophrenia (Kreyenbuhl et al., 2010). Supported employment targets job development through assistance with job searches, ongoing job support and integration of vocational and mental health services. In contrast, Gioia (2005) found that keeping a person diagnosed with schizophrenia in sheltered and supportive employment diminishes the person's success at securing, maintaining and finding value in employment because it prevents the development of competitive work skills and development of career goals.

In institutional settings, token economy interventions use positive reinforcement to shape targeted behaviors (Kreyenbuhl et al., 2010). This system only works within a highly managed treatment care system. Behaviors learned through this intervention help individuals adapt to the institutional setting but translate poorly to community based independent living.

Skills training develops independent living skills and social interaction skills (Kreyenbuhl et al., 2010). Family-based interventions were supported for those people with schizophrenia who continue to have contact with their families. Long-term family interventions have the most significant impact on reducing rates of relapse and recurring hospitalization. Cognitive behavioral therapy (CBT) was also supported by the PORT study and is to be used only in conjunction with psychopharmacological interventions. In another meta-analysis, Lynch, Laws, and McKenna (2010) found that CBT was not effective in reducing symptoms of schizophrenia or in preventing relapse of symptoms. Other interventions supported by PORT were targeted to alcohol and other drug use disorders and weight management (Kreyenbuhl et al., 2010).

**Treatment seeking.** Mental health interventions are rarely chosen or sought by individuals with severe mental illness. Treatment usually begins when a person begins to act bizarrely and family members become concerned or when he or she comes into contact with the legal system. Nine in ten prisoners display signs of mental health problems (Gray, Bressington, Lathlean, & Mills, 2008). Ten percent of male and 14 percent of female prisoners demonstrated symptoms of psychosis. Treatment is prescribed to manage symptoms and behavior seen as unpredictable or dangerous.

Psychopharmacological medications are used in prisons to manage behavior and chemically restrain otherwise violent prisoners. Forced treatment with antipsychotic medication is common and leads to poor long-term treatment outcomes. People reject and avoid future services after being forced to take medications or undergo other psychosocial interventions (Bassman, 2005). Even force through verbal persuasion has negative impacts on attitudes towards treatment, treatment seeking and compliance, and psychological well-being (Luckstead & Coursey, 1995).

Similarly problematic are the social benefit systems including Social Security, Medicare/Medicaid, Bureau of Vocational Rehabilitation and welfare. These systems are constructed through the medical model and view recovery as linear. Once recovery is achieved through an intervention for a set time period, the individual is released from services and loses benefits. These benefits cannot be accessed again as symptoms later increase, as part of the natural cycle of severe mental illness, because doing well excludes the possibility of having a disability (Onken & Slaten, 2000). Many people diagnosed with severe mental illness then feel excluded from employment or are not encouraged to work because of the risk to benefits that employment may pose. People with mental illness may be seen as unemployable, lazy and irresponsible because of this exclusion from the workforce that inhibits integration into larger society.

Other barriers to treatment seeking have been identified. Gulliver et al. (2010) conducted a meta-analysis of studies that investigated treatment seeking in young adults who presented with depression and anxiety. The authors found that only an estimated 35 percent of adults with any form of mental health disorder seek help. Perceived stigma and embarrassment were identified as the largest barriers to seeking mental health care.

Other barriers to treatment seeking included problems recognizing symptoms, preference for self-reliance, lack of accessibility, concerns about confidentiality and trust, concern about the provider, limited knowledge of mental health services, and fear and stress about the act of treatment-seeking. The authors identified fewer facilitators for treatment seeking – perceived positive past experiences, and social support and encouragement from others. For many the experience of previous treatment is negative. Members of the survivor movement see psychiatric treatment as an attack (Bassman, 2000). Previous negative experiences of pressure and force in treatment significantly diminish future treatment seeking (Lucksted & Coursey, 1995).

### **Recovery and Outcomes**

Outcomes for evidence-based psychosocial interventions are measured by reduced time spent in the hospital, increased time spent in housing, decreased episodes of acting out within an institutional setting, decrease in crime, and increased medication compliance (Kreyenbuhl et al., 2010). These outcome measurements are based on time-specific snapshots measuring recidivism and symptom reduction while ignoring the nonlinear development of recovery (Bassman, 2005). Outcomes are measured according to the medical model of disability in terms of cure, cost and remission because the medical model conceptualizes recovery as a linear process (Lysaker, Roe, & Buck, 2010; Rudge & Morse, 2001). These evidence-based practices are not proactive and operate from the limited scope of the medical model that defines outcomes on the basis of reduction in symptoms and cost of care rather than by increases in quality of life. In addition, these approaches ignore the multiple levels of trauma that people with severe mental illness are managing in the recovery process (Spaniol et al., 1999). There is a

recovery from the illness, from the impacts of medical treatment including the negative attitudes and lack of skill of many of the helping professionals, from the devaluing and disempowering environment, from the lack of enriching opportunities, and from the impact of stigma and discrimination in society. Few of the evidence-based interventions support independent living and none use the social minority model of disability to approach identity integration and political, economic, and social changes to increase integration into the larger community. Andresen, Caputi, and Oades (2010) found that there is no relationship between consumer-defined recovery and clinical outcome measures.

Recovery has a changing definition and currently reflects the greater voice of the community of those with psychiatric disability. Older definitions of recovery allowed only for a discrete period of time when health is entirely regained (Resnick, Fontana, Lehman, & Rosenheck, 2005). The recovery movement has grown out of the social minority movement and places the person diagnosed with severe mental illness at the core of the treatment decision process (Bassman, 1997; Olkin, 2002). The recovery process should be initiated by the person with diagnoses of severe mental illness and driven by hope (Lysaker et al., 2010). An individually defined recovery develops from the establishment of a fulfilling, meaningful life with an affirmation of identity (Andresen, Oades, & Caputi, 2003).

Recovery is individually variable although Davidson, O'Connell, Tondora, Lawless, and Evans (2005) identified nine common elements to recovery: renewing hope and commitment, redefining self, incorporating illness, being involved in meaningful activities, overcoming stigma, assuming control, becoming empowered, managing

symptoms and being supported by others. This is different from a “cure” in that recovery is more about finding ways to live with the diagnosis of severe mental illness and figuring out ways to live as part of their everyday lives (Borg & Davidson, 2008).

The Davidson et al. (2005) model of recovery, described above, employs a different set of criteria than traditional outcomes and requires a different set of outcome measurements that address the common elements of this definition of recovery. Assessment tools used in some studies of recovery have included the Positive and Negative Syndrome Scale (PANSS) and the Brief Psychiatric Rating Scale (BPRS) (Lysaker et al., 2010). The PANSS assesses for schizophrenia symptoms of hallucinations and delusions, and also examines negative symptoms and impact on social withdrawal and isolation. The BPRS assesses not only for the presence of positive and negative symptoms, but also for role functioning with family, friends and work, independent living, and meaningful social connection. Ritsher, Otilingam and Grajales (2003) developed an Internalized Stigma of Mental Illness scale that evaluates experiences of discrimination, stereotyped beliefs, and infiltration of stigma into the individual’s personal identity.

A central tenet of the recovery movement is psycho-education about the nature of mental illness and all the various treatments and interventions available (Davidson, 2010). With this information people diagnosed with severe mental illness are able to make informed treatment decisions. Recovery from a provider perspective means offering access to treatments and community services that are effective in decreasing symptoms, thus assisting in enabling people to lead productive and meaningful lives (Shean, 2009). From the perspective of those engaged in the recovery process all

experiences that foster healing are important. Positive changes in attitudes, feelings, perceptions, beliefs, goals and roles are associated with increased involvement in the process of self-renewal, independence, and responsibility (Spaniol et al., 1999).

Outcomes within this definition of recovery are measured by symptom remission, involvement in work or school, independent living without close supervision, no full dependence on financial support from disability insurance, and having friends with whom activities are shared on a regular basis.

### **Disability Identity Development Models**

Other minority populations have fought to establish group identity in the face of oppression and in reaction to being outside Western cultural norms. The dominant person is Anglo-Saxon, middle class, male, Christian, heterosexual, English speaking, young, with no history of physical or psychiatric disability (Reynolds & Pope, 1991).

Different minority groups, who are outside of these rigid norms, have reacted against microaggressions and oppression to fight for their right to be (Sue & Capodilupo, 2008). Women, racial minorities, and gay and lesbian people have developed a community of identity in response to sexism, racism, and heterosexism. However, as long as the medical model prevails, there is no need for the disability population to fight for identity against ableism because “cures” are supposed to eliminate the presence of disability. In treating severe mental illness, the medical model does not allow for disability identity development because the goal of treatment is a return to “normalcy” and an elimination of the impairment. Social minority model advocates would link the right to claim disability identity to that of any other minority status (Bassman, 2000).



Not allowing someone to establish a disability identity is the same as not allowing a woman to identify as a woman.

**Models of disability identity development.** Models of disability identity have embraced the social minority model to include conceptualizations for integration into larger society and for the formation of a disability community. Models of disability will be discussed in relation to their effectiveness in accounting for the disability identity formation in people with severe mental illness.

***Integration model.*** Integrative models of disability provide frameworks for understanding disability by recognizing the impact of the environmental system, the personal system, the mediating factors of disability such as appraisal, activation and adaptation, in addition to health status and treatment seeking and compliance behavior (Tate & Pledger, 2003). In recognizing the ways these variables interact, integration model of disability identity development provides a framework to applying the social minority model to the development of individuals.

Gill (1997) proposed a model that included four types of integration as a becoming process for people with disabilities. The first level is the integration into society and development of a feeling of belongingness, including an assertion of the right to inclusion and participation in dominant society. The second level is integration with the disability community. Some people with disabilities avoid contact within the disability community because of internalized devaluation and rejection of people with disabilities. In the third level, the person with a disability works to internally integrate the parts of his or her self that are and are not impacted by disability. The medical model and dominant society guides people to embrace abilities not impacted by disability and

reject or ignore the disability. In this perspective, the whole person can never be acceptable and the learned rejection prohibits integration. Growth develops from an acceptance of difference and affirmation comes from separation from the dominant culture that devalues disability and difference. The last level of integration is in integrating the affirmation of disability with public identity. Some people with invisible disabilities are able to maintain the secret and “pass” as someone without a disability.

This model does not explicitly address psychiatric disability identity formation, and many of the model’s features do not apply to a person diagnosed with severe mental illness (Gill, 1997). For example, in the third level of this model -- integrating internally rejected and affirmed parts of the self -- growth comes from acceptance of difference and the refusal to apologize for that difference. People diagnosed with severe mental illness are not allowed to stop apologizing for their differences because the goal of traditional treatment approaches is to return to “normal.” Moreover, symptoms of severe mental illness are episodic, cyclical and chronic. Reconstructing the self with the experience of severe mental illness differs from processes of identity development in other marginalized groups because there are less clearly defined parameters of the experiences and these parameters change due to the cyclical nature of severe mental illness (Onken & Slaten, 2000). Gill’s (1997) model does not account for disabilities that are cyclical like severe mental illness.

***Severe mental illness integration model.*** While severe mental illness is understood as a brain disorder within the medical model, the experience of the illness affects the core being of individuals (Shea, 2009). In severe mental illness, there is a loss of a sense of self and this needs to be overcome, or managed, for recovery to take place

(Wisdom et al., 2008). People diagnosed with severe mental illness tend to have lower self-esteem, self-worth and sense of self-identity (Perese, 2007). The process of recovery involves an engagement with the illness to learn about its management and symptoms – adopting an “illness identity” is a part of this immersion process.

Onken and Slaten (2000) proposed a framework for developing positive disability identity in regard to severe mental illness using the social minority model of disability. This model recognizes community as central to the development of disability identity and the role that challenging ableism plays in the affirmation of severe mental illness experiences. The process is nonlinear, fluid, non-sequential, complex and movement occurs between and across the multiple states of the framework. The framework proposes seven states of identity development.

As the process begins, the person with a severe mental illness is in a state of preawareness conformity or denial (Onken & Slaten, 2000). In this state, the person accepts without judgment the medical model of psychiatric disability and the dominant society’s social construction of disability and ableism. The person may ignore or conceal the presence of mental health concerns, work to conform to ableist society and blame personal deficits for failures.

Within the next state, contact and comparison, the person with severe mental illness is exposed to alternative views of disability and challenges to the medical model (Onken & Slaten, 2000). The person may become aware of reasons for feeling different and outside the ableist dominant society. The person may begin to recognize the disadvantages, limitations, and disempowerment of the ableist treatment practices of the medical model paradigm.

In the confusion and dissonance state, the person with severe mental illness experiences identity confusion and conflict as he or she begins to challenge internalized ableist beliefs and values (Onken & Slaten, 2000). There may be a sense of growing personal isolation because the person with severe mental illness has lost a sense of group identity within dominant society and has not yet developed a sense of group identity with the disability community.

Tolerance and connection is a state where the person with severe mental illness begins to experiment with disability membership and identity (Onken & Slaten, 2000). The person may begin establishing a network of support within the disability community. This is a precursor to the immersion and resistance state where the person with a severe mental illness may retreat from ableist society as much as possible, become immersed in the identified disability group, and seek self-help and peer-support opportunities rather than traditional treatment supports.

Within the state of acceptance and pride, the person with severe mental illness sees disability more positively and develops a growing respect for others with similar disabilities (Onken & Slaten, 2000). The person works to expand knowledge about personal disability and resources. The person is able to label ableist microaggressions, values, beliefs, attitudes and behaviors and may begin challenging ableism.

The final state, introspection and synthesis, integrates current and past group memberships and identities (Onken & Slaten, 2000). The person with severe mental illness experiences increasing integration of view of self, identity and personal autonomy. The person experiences a sense of empowerment, pride, and affirmation from identity.

The person works to become competent in disabled and non-disabled communities, is able to develop allies and to personally challenge the narrow views of ableism.

Disability identity is firmly rooted within the development of a community, an affirmative support system for the person with severe mental illness (Onken & Slaten, 2000). This model works to combat the shame experienced by persons diagnosed with severe mental illness within dominant ableist society. Given that identity development is a highly personal, subjective and self-defined process further investigation is warranted into its impact on recovery, treatment seeking, and compliance (Yanos et al., 2010).

**Internalized ableism and shame.** Developing a positive disability identity requires recognition of the oppression directed at the disability community by the dominant society's ableist values, beliefs and behaviors. Ableism is the set of negative assumptions and practices that systematically promote physical, mental, or behavioral disabilities (Onken & Slaten, 2000). Internalizing these negative societal assumptions about disability and experiencing devaluation by others leads people with disabilities to devalue themselves. The difference of having a disability does not need to be significant to be devalued, particularly in a dominant society that values perfection.

The oppression of ableism takes multiple forms. Microaggressions are short, everyday messages that are denigrating to minority groups (Sue & Capodilupo, 2008). These messages can be verbal, nonverbal, or visual behavior that can be done automatically, unconsciously, and delivered intentionally or unintentionally.

In the dominant ableist society, disability and severe mental illness are not talked about – there is a silence that surrounds disability (Onken & Slaten, 2000). Mental health problems are kept secret and hidden. A person with a severe mental illness may tell a

few trusted others but will likely face rejection and avoidance from others. Fighting this fear and silence, taking pride in disability and the disability community reduces shame and it “breaks the prison of silence” (p. 103).

Stigmatization is the chronic negative interaction with the environment that people with severe mental illness face on a constant basis (van Zelst, 2009).

Stigmatization is a stereotyped set of negative attitudes, incorrect beliefs and fears about the diagnosis of severe mental illness that impacts how the person with severe mental illness and others understand the diagnosis. Internalized stigma is the psychological impact of societal stigma (Ritsher & Phelan, 2004). Internalized stigma increases avoidant coping, social avoidance, and depressive symptoms (Yanos, Roe, Markus, & Lysaker, 2008).

Stigmatization leads to discrimination (van Zelst, 2009). Discrimination leads to poor access to health care and services and results in poorer treatment compliance. Discrimination is a chronic stressor that can trigger increased symptoms of schizophrenia. Stigma creates barriers to accessing safe housing, employment, integration in the community, and increased poverty and victimization (Perese, 2007). This results in a worsening of symptoms of the disorder and a decreased quality of life.

Internalized stigmatization can lead to label avoidance and denial about the diagnosis of severe mental illness (van Zelst, 2009). This leads to a delay in treatment seeking and decrease treatment compliance. The threat of social rejection and discrimination that comes with the diagnosis of severe mental illness may account for the under-use of mental health services.

Since stigmatization is an environmental risk factor, it is also a modifiable risk (van Zelst, 2009). To combat stigma, people's attitudes need to change through increasing education, raising community awareness, changing public policies to reduce discrimination and ensuring access to treatment (Villares & Sartorius, 2003). There is some push to change the labels associated with severe mental illness to increase treatment provider communication, education and stigma reduction (Levin, 2009). In Japan, the name for schizophrenia was changed from "mind-split disease" to "integration disorder," and this has substantively reduced the association with violence and criminality.

**Schizophrenics Anonymous.** Schizophrenics Anonymous (S.A.) was established in 1985 in the Detroit, Michigan, area as a self-help peer support group for persons diagnosed with schizophrenia or a schizophrenia-related disorder (Schizophrenia and Related Disorders Alliance of America [SARDAA], 2010). Schizophrenics Anonymous is administered in partnership with SARDAA and is operated and managed by persons experiencing schizophrenia or a related disorder. S.A. groups with consumer leaders had greater longevity than groups lead by mental health professionals (Salem, Reischl, & Randall, 2008). The mission of Schizophrenics Anonymous is "to add the element of self-help peer support to the recovery process of people suffering from schizophrenia and related disorders. We hope this resource will contribute to the sense of well-being of S.A. members and will help us cope with the challenges imposed by our illness" (SARDAA, 2010, p. 4).

The Schizophrenics Anonymous statement of purpose is as follows: "To help restore dignity and sense of purpose for persons who are working for recovery from schizophrenia or related disorders. To offer fellowship, positive support, and

companionship in order to achieve optimum mental health. To improve our own attitudes about our lives and our illness. To provide members with the latest information regarding schizophrenia and related disorders. To encourage members to take positive steps toward recovery from the illness.” (SARDAA, 2010, p. 4). The mission of S.A. reflects an understanding and application of the social minority model of disability. Schizophrenics Anonymous exists to provide a supportive environment that promotes a recovery model that is focused on learning to manage and live with symptoms rather than eliminate those symptoms. Recovery is done through learning to manage the disorder within the person’s life, family, and community.

Each Schizophrenics Anonymous group varies in their level of structure dependent on membership, presenting concerns, leadership, and location. However, all S.A. groups generally follow the “Six Steps for Recovery” wherein each step promotes the S.A. view of recovery as learning to manage, cope, and live with the diagnosis of schizophrenia or a related disorder. The first step, “I surrender” relates to accepting the need for help and the acknowledgment that recovery cannot be done entirely alone (SARDAA, 2010). In contrast to wider societal values of independence, this step frames interdependence as a value and as an essential first step towards recovery from schizophrenia-spectrum disorders. The second step, “I choose” means the person in recovery chooses to be well and to recognize choice as an agent of change and personal responsibility. The third step, “I believe” means the person in recovery has the inner resources to help him or her self and others. The fourth step, “I forgive” is a process of learning to forgive past mistakes. “I understand,” the fifth step, guides the person in recovery to understand how “erroneous, self-defeating thinking contributes” (p. 5) to



personal problems and unhappiness and then directs the person in recovery to change this thinking system in an effort to change how he or she views his or her life. The final step, “I decide” involves a choice to surrender to a “Higher Power” in order to change. These six steps form the core of a S.A. group’s mission and reflect the history of Alcoholics Anonymous and the disability rights movements.

## **Conclusion**

Stigmatization of severe mental illness impacts treatment seeking and compliance. Stigmatization arises from the negative attitudes, beliefs and discriminatory behavior of the dominant ableist society towards difference and disability. Knowledge of the history of disability is important to understanding the social conceptualization of psychiatric disability and how that understanding impacts treatment for severe mental illness. Originally, disability was understood through the moral model, this model remains, albeit more covertly, though the medical model has largely supplanted it. The medical model views disability as a pathological problem, psychiatric disability is viewed negatively and efforts are made to cure it. The medical model continues to inform medical and mental health interventions (Olkin, 2002).

Given the prevalence of the medical model, severe mental illness is seen as a brain disorder and treatment is focused on eliminating the disorder through prevention, psychopharmacological medications, and psychotherapy (Insel, 2011, August 12). Treatments based on this view of severe mental illness focus on eliminating the disorder and do not allow the possibility of forming a disability identity based on other models of recovery. Interventions that address the effects of stigmatization and disability identity formation have not been developed and tested (Yanos et al., 2008).

Within the disability community, the social minority model is presented as an alternative model for conceptualizing disability. New definitions of disability have led to new definitions of recovery where people with severe mental illness may benefit from learning to live with the disability and take pride in their disability status and community. The social minority model of disability and changing definitions of recovery have challenged outcome parameters for people diagnosed with severe mental illness. The more a person learns how to live with severe mental illness, the less severe the illness becomes (Davidson, 2010). Integrating and living with the diagnosis of severe mental illness is mediated by the internalized stigma and shame associated with it (Yanos et al., 2010). By exploring the lived experience of people with severe mental illness, the role of stigma and the impact of the medical model can be identified as barriers to treatment seeking and compliance, and it can be established that positive disability identity formation can play a facilitative role in treatment seeking and compliance behavior in people diagnosed with severe mental illness.

## **CHAPTER 3**

### **Method**

#### **Qualitative Research**

The debate in the research field over the benefits, integrity, and reliability of qualitative research is ongoing. Historically, psychological research has relied on quantitative methods and these methods have been viewed as superior to qualitative research (Gelo, Braakmann, & Benetka, 2008; Kidd & Kral, 2005). Qualitative researchers argue that, in answering research questions posed by real-life problems, this approach benefits from being exploratory and recognizing social construction of reality. Qualitative research can be defined as an interpretive practice that studies the natural environment by collecting, analyzing, and understanding the meanings people ascribe to the lived experience of the research problem (Leisey, 2008). Given the recognition of the subjective nature of participants' lived experience, qualitative research methods acknowledge the impact of personal experience, action and culture (Gelo et al., 2008).

#### **Participatory Action Research**

Participatory action research provides ideas for more constructive partnerships between people diagnosed with severe mental illness and clinicians (Magliano et al., 2008). Participatory action research (PAR) is a model of qualitative research that involves participants in the research and uses the research to enact societal change and change in the lives of those participants (Ponterotto, 2010). Kidd and Kral (2005) described PAR simply as “you get the people affected by a problem together, figure out

what is going on as a group, and then do something about it” (p. 187). The focus of the PAR method is less on the research question, but on the process of the research and the problem to be solved. PAR produces information that will be introduced back into the community to address the problem and then become a part of the ongoing process of research. The hallmark of PAR is its cyclical nature (Cook et al., 2010). This creates a multiple sequences of self-reflective cycles composed of reflecting on the problem, planning action, acting, observing, and reflecting on the results and impact on the problem (Kidd & Kral, 2005). Given this self-reflective spiral, the PAR researcher must be involved in the process and in the community. Professional researchers form partnerships with community members to identify issues, to develop ways of studying these issues, and to take action on the resulting knowledge (Smith, Bratini, Chambers, Jensen, & Romero, 2010). Success of a PAR project relies on commitment and responsibility to the partnership (Kidd & Kral, 2005).

Community-based PAR offers a method to empower minority communities and democratize the production of knowledge (Smith et al., 2010). There is a natural relationship between PAR and the clinical researcher’s commitment to social equity and action. PAR has the potential to create knowledge from within minority communities that does not reproduce the worldviews, values and interests of dominant groups. The relationship between researcher and the research subjects is dramatically different and is a power-sharing challenge to traditional research approaches. Local methods for gathering knowledge are recognized as valid and PAR researchers learn about the lived experiences of the research participants (Kidd & Kral, 2005).

Since PAR is a fluid, multifaceted, co-created, idiosyncratic process, these research projects do not always correspond to traditional report-writing protocols and evaluations (Smith, Rosenzweig, & Schmidt, 2010). PAR does not propose a clear set of procedures (Ponterotto, 2010). In reporting PAR, it is important to place the experience and knowledge in its context by giving detailed descriptions of the participants and their various roles, reflecting on the created knowledge, and discussing changes for the people involved, including the researcher (Kidd & Kral, 2005). The researcher must write about his or her personal experience and involvement in the research process (Smith et al., 2010). Evaluating PAR for publication by scientific standards can be done. Evaluation should be done with caution because traditional approaches to evaluation can devalue local modes of knowledge, action, and evaluation. (Kidd & Kral, 2005). Evaluation can disrupt egalitarian relationships between researchers and participants. Scientific evaluation relies on replication given that previous PAR projects provide guidelines for future research. Validity can be determined through evaluation by examining multiple perspectives and using face validity with participants.

### **Participants**

Participants for this study were recruited from a Schizophrenics Anonymous group in the Dayton, Ohio area. Schizophrenics Anonymous is a self-help group for persons diagnosed with schizophrenia-spectrum disorders (Schizophrenia and Related Disorders Alliance of America [SARDAA], 2008, November 27). Seven participants were recruited to participate. Inclusion criteria for this study required participants to have a diagnosis of a schizophrenia-spectrum disorder. Exclusion criteria included people without a diagnosis of a schizophrenia-spectrum disorder.

## **Materials**

All materials used throughout this study were approved by the Institutional Review Board at Wright State University. On the day of the scheduled interview, each participant was provided an informed consent form (Appendix C) detailing his or her participation in the study to review and sign. Next, participants were given a brief, anonymous demographic form (Appendix E) to complete, asking information including gender, age, ethnicity, diagnosis, religious affiliation, education level, family composition, military background, and occupation.

The primary investigator conducted each interview. All interviews were audio taped and followed an interview protocol (Appendix B). In the interviews, the primary investigator introduced the research purpose, completed a consent form with the participant (Appendix C), asked the participant to complete a demographics form (Appendix E), and asked a series of eight questions about the interview subject's lived experience as a person diagnosed with schizophrenia or schizoaffective disorder (Appendix A). The first question asked the participant about when and how he or she learned about his or her diagnosis or became mentally ill. The next two questions explored further the participant's view of his or her diagnosis and how the participant's social support system reacted to his or her diagnosis. The next question asked about the participant's involvement in treatment. The next three questions explored the participant's views of recovery, what role medications play in recovery, and what has had the greatest impact in his or her personal recovery. The final question asked the participant to identify what he or she wanted people without schizophrenia or

schizoaffective disorder to know about his or her lived experience of being diagnosed with schizophrenia or schizoaffective disorder.

## **Procedure**

Human Subjects approval was granted through the Wright State University Institutional Review Board (IRB). Given the PAR approach of this research, members of a Schizophrenics Anonymous group were partnered with the investigator to inform the researcher as to questions clinicians should be asking about the relationship between psychiatric disability identification and treatment seeking and compliance. Members of this group have all been diagnosed with schizophrenia or schizoaffective disorder. A letter (Appendix D) outlining eligibility requirements was distributed to members who attend the Dayton Schizophrenics Anonymous group. Individuals meeting the requirements outlined in Appendix D were asked to contact the primary researcher through provided contact information.

Participants who contacted the researcher set up an hour-long meeting with the researcher at a location that ensured confidentiality of the participant. The researcher first asked each participant to complete the consent form (Appendix C) and demographic form (Appendix E) followed by the interview. Interviews were conducted in a semi-structured format, following the questions outlined in Appendix A.

Following the interviews, sessions were transcribed and sanitized to remove identifying information. Transcriptions are provided in Appendix F. Analysis of the data followed the participatory action research approach discussed above to identify information about the hypothesis that a positive disability identity is a facilitator for treatment seeking and compliance in people diagnosed with severe mental illness.

Coding of data followed the Auerbach and Silverstein (2003) model for analyzing qualitative data. Relevant text was selected from interview data for further analysis. The next stage involved grouping together repeating ideas into coherent categories and identifying themes. Finally, themes were grouped into more abstract concepts that reflected the expected results related to the connection between the positive sense of self, associated with the rejection of ableism and the development of a positive disability identity, and the willingness to take medications and engage in treatment.



## CHAPTER 4

### Results

#### Demographics

Each participant was asked to complete a demographics form (Appendix E) to obtain basic information about gender, age, ethnicity, relationship status, highest level of education, and religion/spirituality. Names have been changed to protect confidentiality. Table 1 presents this information provided by participants and Table 2 presents additional information provided by participants about occupation, military experience, social support, and family composition.

Table 1

#### *Demographics of participants*

Participant	Age	Gender	Ethnicity	Relationship Status	Highest Level of Education	Religion/Spirituality
1 – Rebecca	45	F	White	Single	B.A.	Evangelical Christian
2 – Frank	61	M	African-American	Divorced	Some college	Methodist
3 – Ethel	55	F	White	Single	B.S.	Seventh-Day Adventist
4 – Earl	61	M	White	Single	B.A.	Roman Catholic
5 – Donna	61	F	White	Single	Some college	Seventh-Day Adventist

6 – Eddie	70	M	White	Married	B.A.	Evangelical Christian
7 – Carl	37	M	African-American	Single	Some college	Southern Baptist

Table 2

*Additional demographics of participants*

Participant	Occupation	Military Background	Social Support	Family Composition
1 – Rebecca	Unemployed	N/A	Friend [L] from church	Mom, dad, younger brother
2 – Frank	Retired	Air Force	(blank)	(blank)
3 – Ethel	Unemployed	N/A	[M], SDA church members, prayer group	I live by myself
4 – Earl	Teaching degree	No	S.A., [Catholic] parish	6 brothers and sisters, lives with mom and dad
5 – Donna	(blank)	(blank)	S.A., [CMHC], neighbors	I am the youngest
6 – Eddie	Retired (accountant)	No	Church, S.A.	Wife, 3 children (all grown and out of the house), grandchildren
7 – Carl	N/A	N/A	[CMHC] (a community agency), and S.A.	Mom

**Diagnostic variables of the participants.** As part of the demographics form (Appendix E), participants were asked to provide information about their current and past mental health diagnoses, age of onset of mental health concerns, and other health concerns. Table 3 presents this information.

Table 3

*Diagnostic variables of the participants*

Participant	Current MH Diagnoses	Previous MH Diagnoses	Age of Onset	Health Concerns
1 – Rebecca	Schizoaffective disorder, Bipolar type	Major Depression; Schizoaffective; Obsessive-Compulsive Disorder	19	Under active thyroid; Urgency of urination; Overactive bladder; High pulse
2 – Frank	Schizoaffective/ Bipolar	Paranoid Schizophrenia	23	Heart rhythm; Cholesterol
3 – Ethel	Schizoaffective disorder; Mild depression	Schizoaffective disorder	20-21	Seizures; Gastric reflex; Constipation
4 – Earl	? (Schizoaffective)	Schizophrenia	24	None
5 – Donna	Schizophrenia	Paranoid schizophrenia	19	Knee arthritis; Broke wrist
6 – Eddie	Doctor has not told me (Schizophrenia)	Schizophrenia	35	Asthma; Knee problems; Blood pressure
7 – Carl	Paranoia-Schizoaffective disorder	Schizophrenia	16	Obesity

Of the seven participants, five identified having a form or subtype of schizoaffective disorder, and two identified having a diagnosis of schizophrenia. One participant reported having schizoaffective disorder and an additional diagnosis of “mild depression.” Throughout the interviews, one participant disclosed a history of Obsessive-Compulsive Disorder, another participant reported a history of Posttraumatic Stress Disorder, and another participant reported a history of Bipolar Disorder, but felt that it was an inaccurate diagnosis.

## **Interview Responses**

Each participant answered every question on the interview protocol. The following is a summation of the answers provided by the participants. Interview data was coded using Auerbach and Silverstein's (2003) approach to qualitative data coding and analysis.

**Question 1: When and how did you know you had schizophrenia or schizoaffective disorder?** Each participant learned of his or her diagnosis from others, typically medical professionals. Earl learned that he had schizophrenia during his first hospitalization that followed a psychotic episode where he believed he was a pilot. He joked, "Later that afternoon, instead of being a sky pilot ... I got shot down" when involuntarily hospitalized and diagnosed with a severe mental illness. Ethel stated, "Well everybody told me" about her diagnosis after she was hospitalized for bizarre behavior while in college. Another participant, Eddie, shared that, in 1975, his family doctor ...put me on Valium and that wasn't cutting it. So in '77, I was walking around the neighborhood trying to get into houses. ... In '77, was when I was first diagnosed with schizophrenia. ... But I wasn't diagnosed in '75.... It was very confusing around then.

Several participants shared that they do not remember being told about his or her diagnosis after an extended period of confusion and engagement in treatment. Donna shared that she was diagnosed as a teenager. She stated, "I kept saying, 'What's wrong with me? What's going on?' and nobody could tell me." She learned about her diagnosis by accident. She stated,

I saw on the paper that he had my name down as paranoid schizophrenic. Yeah. And I saw that and that's when I thought that I was diagnosed. That's the only way I knew. My psychiatrist sent him over some information about me. They never told me anything.

She stated, "If they had told me sooner, I would be better." Frank shared that he was hospitalized for an extended amount of time while in the military and was not informed of his diagnosis until he was discharged from the military because of his disability. When asked if he was told what his diagnosis was, he stated, "They probably did have a diagnosis but didn't tell me... They wanted to withhold that diagnosis because it might change."

Other participants learned about diagnosis earlier in the course of his or her severe mental illness. Carl shared that he was diagnosed with schizophrenia at age 16. He was "angry because of the stigma" of mental illness. He shared that, at the time, he believed that schizophrenia meant that he had "multiple personalities, but I knew that wasn't true. ... But later I found out what the major symptoms are ... and today, I'm glad." Rebecca believed that she had schizophrenia as a child and recognized her symptoms in a health class in high school. She stated,

I was a teenager and the teacher in health taught about schizophrenia, about catatonic schizophrenia, and I thought I would be angry enough to just sit there and wait and not respond and have people like want to move me, and I wouldn't react out of anger and I thought that's why I had schizophrenia. Then this girl stood up and talked about schizophrenia in her speech and I said, "That's me!" I got schizophrenia.

She was formally diagnosed while in college following a “breakdown” and received medication treatment at that time. She felt that medication would have been helpful to her as a child, but did not become involved in treatment until she was teenager.

**Question 2: What do you think about your diagnosis? Do you agree with your diagnosis?** Six of seven participants shared that they felt they were accurately diagnosed with schizophrenia or a schizophrenia-related disorder at the time of the interviews. Rebecca stated, “It’s very true.” Ethel did not believe that her diagnosis was accurate. At the time of the interview, Ethel stated, “I don’t know what my current mental health diagnosis is.” Others shared that knowing their diagnosis was helpful. When Frank learned about his diagnosis, he stated, “It seemed to be a relief.” Donna stated, “The greatest thing that helped me feel better was to know that I was a schizophrenic.”

Both Carl and Earl, when initially diagnosed with a severe mental illness, thought the diagnosis of schizophrenia meant having multiple personality disorder. Earl stated, “They talked about my diagnoses as being about split personality. It’s an interesting one, but schizoaffective makes more sense than split personality.” About his current diagnosis, Earl feels that it’s “both yes and no.” He identified that he has trouble “accepting” his diagnosis at times and feels that this is also a symptom of his illness.

Eddie shared that he has had a previous diagnosis of Bipolar Disorder. He shared the following,

Now I’ve had different psychologists, people in your position, diagnose me as bipolar. ... Well it did because my brother was bipolar, so they thought I was

bipolar, but I was going through some more situations. Because of another situation I can understand the schizophrenia.

**Question 3: How did your family and friends react to your diagnosis?** All participants reported having relationships with family at the time of the interviews. Ethel shared some frustration with her family because they insist that she takes her medications, “even though it wasn’t working” for several years. Donna shared that her “dad was guilt and guilt. My mom was guilt and guilt,” when they learned about her diagnosis. Her brother was also diagnosed with a mental illness at the time, and she shared that her parents visited them regularly in the hospital and she felt supported by her family.

Eddie shared that his family was not supportive, his parents “did not accept me... because of the psychiatry they don’t. The church doesn’t go along with, and my parents don’t go with, my diagnosis. ...They don’t believe in psychiatry. ...[Mental illness] is the sinful nature. It’s still the sinful nature.”

Carl shared that his family “reacted good. I’m not sure. As far as my immediate family, they did.” Frank shared that his family has been supportive of him, even when he feels he does not deserve their support. He shared the following:

So they put that in the diagnosis and when my mom found out, no one in our family ever had a mental disorder. They said to me, they said, that they loved me and they would do anything for me to make me better. They supported me. They didn’t ostracize me from the family. But I was at a point in my life, I thought if I’m behaving this way, then I cannot be a member of the family. I did not want to live up to the name of my family because I wasn’t. It just didn’t seem like I was

able to because of this diagnosis and the way my behavior was. ...My mom would come by to see me and she would bring me groceries and, you know, help out. And my brother, he tried to get me involved in sports again and I just couldn't.

Rebecca also expressed surprise at the support she has received from family. Rebecca shared that her parents were "petrified" when she was first treated for severe mental illness. She was away at college and her parents were upset and confused. She initially refused to call them. At the time of the interview, she described them as supportive and active in her treatment. She shared that her "dad says that I have triumphed over mental illness" and that he is "proud of her."

While Earl remains close with his family, he shared that, "the friends I had, peer groups in the past... the beer drinkers, you know, they quit hanging out with me. ...I just didn't hear from them anymore." Frank also shared that he "ended up being a loner" and discussed having few friendships. Carl also shared that he felt alienated from peers and that his mental illness has impacted his romantic relationships. He stated,

There was this young lady that I knew from school and I don't know what possessed me to do this, and even now when I think about it, it makes me anxious as you now notice. I wanted to date her ...and something told me, 'Don't do that.' And I regret a little bit.

Eddie shared that it was church community members and his wife's employers that supported him when he was involved with the legal system.

**Question 4: How did you get involved in treatment?** Six of seven participants described being involuntarily hospitalized as their first interaction with treatment



systems. Most participants shared experiences of multiple hospitalizations. Rebecca shared, “I had a breakdown and went in the hospital and got on psych meds... So that’s how I knew I was sick.” She reported that she has been “in and out of the hospital for 26 years.”

Donna shared that her parents were “sneaky” and they

...got a mental inquest warrant. If you get a psychiatrist to tell the police that you are mentally ill, they will come and take you to the hospital. ...They told me they wanted me to talk to a psychiatrists, all sneaky you know? And I talked to a psychiatrist and they said I think you should stay here a couple weeks.

When asked when she started to engage voluntarily in treatment, she said, “Oh, well, yes, when I was in my 50s. ...It was in my 50s when I knew I was paranoid schizophrenic, maybe when I started coming [to S.A. meetings], but I’m not sure.”

Similarly, Frank and Earl described being asked to talk with someone and then being sent to the hospital unexpectedly. Earl shared the following story.

I was going to be an interceptor pilot. ...Mom was at the office at [Church] and I went over there to see how she was doing to see if I could help her if there was anything I could get for her then she said, “Oh, guy by the name of [Larry] was in here today and why don’t you go over there to [CMHC]... maybe he can help counsel you.” I wasn’t forced to, and it was something that I might be able to go to. I wasn’t working at the time. ...Go see [Larry]. It was just like a fish and the bait. And when I went to see [Larry] he said you go see [Joe]. ...Some guy named Dr. [Joe]. And the doctor says you go over to [Hospital] or go over to St. [X’s].

Frank shared that he was talking to

...the head [officer] for the shift, and they asked me a few questions and he said, “Well, we have the ambulance coming, so we’ll take you there.” And I was on the hospital ward at the [military base] and I was there for three weeks.

Being in the hospital impacted his view of himself. He stated, “Well, I must be really, really sick because they are keeping me in the [hospital].” Later, he identified having support from the S.A. group in treatment. They had a “buddy” to call when needing extra support. He stated,

Well then we could talk to them and you know they’re there for us. You know, it really does help to keep on a good keep and it’s quicker than taking a trip to the hospital and waiting on the doctor for whenever he can see you. ...It makes sense too. I mean, hospitals can be very helpful... but they can also be scary and takes you out of the environment where you’re really comfortable.

Carl was involuntarily hospitalized as a teenager. His “parents decided I needed to go see a psychiatrist because I was saying I wanted to hurt myself and I wish I were dead.” He has had further involuntary treatment periods at hospitals. Carl shared,

I was at the hospital after I turned 20. And that was definitely involuntary because I was so paranoid when I was at the medical center that I thought I was going to die. ...I was in there for a month and after... my psychiatrist asked me to do was go to [CMHC] because it’s a good place so I took her suggestion... I had my medical records transferred there, and I’ve been there ever since.

He stated that at the time of the interview, he was “thankful that I’m getting treated for this.”

Ethel shared that she was surprised when “the next thing I know the police were knocking on the door. ...I was in and out of the hospital every year.” She has engaged in treatment through religion and spirituality. She struggled with medications for many years “until 2006, when I prayed all year and then it was the next year they came out with the right medicine for me.” She identifies her treatment as including focus on her “diet... and walking, getting out, and walking, that has helped a great deal.”

Eddie’s experience of treatment has not involved hospitalization, in contrast to other participants, but he was, at one point, mandated to treatment of his mental illness. He shared that he went to his family doctor and received referrals to psychiatry as his symptoms increased. Following some legal problems, Eddie had to engage in mandated treatment. His wife joined him in his interview and shared that “he had probation and part of that is that he had to take medications.”

**Question 5: How do you define recovery?** Participants identified different personal definitions of recovery. Rebecca shared that she is “recovering” and that recovery meant “bright spots” including periods of time when she felt well and going on vacations with her family. Earl shared that he views recovery as “recuperative reflection” which he described as an “old philosophy” idea that he learned about from a mentor. Ethel defined “recovery by having a relationship with God and salvation through God. I do not find it necessarily through my nurse practitioner because she doesn’t understand me as much as God understands me and gives me hope.”

Other participants defined recovery by an alleviation of symptoms. Eddie stated that recovery is, “Not hearing the voices. Not being in the hospital.” He went on to say that he’s “not recovered because I still have to take the medications.” Carl shared that

recovery means, “just not being in relapse and being positive. So that my life is manageable and things are not out of control and I’m able to get through and not do anything crazy.”

Frank shared,

Recovery for me would be that, instead of getting overly panicked, overly nervous, that the nervousness would only last for, at the most, five to ten minutes, at the most. Normal for me would be to be able to enjoy TV programs... being able to walk outside, down the street, without thinking that someone is talking about me.

Similarly, Donna described recovery as a process where she still has symptoms, and is coping with them. “Exercise, eating right, keeping taking the medicine, and if you’ve got these thoughts, tell your doctor or your therapist.” She also shared that she reads the “blue book” from the S.A. organization and that she “can’t get past Step One: I Surrender. I surrender. I still have the thoughts, the grandiose thoughts so I haven’t surrendered altogether.”

**Question 6: What role does medication play in your recovery?** All participants reported that they were on medications to treat severe mental illness diagnoses. Earl stated that medications are “enlightening.” Medications were identified as essential to recovery. Carl shared,

As long as I take it, I don’t have to worry about going to the hospital and I take it because it does help. And another thing I probably need to work on is figuring out how they work. How each drug is helping me and I know I need to take it in order to stay in recovery.

For Eddie, taking medications means “I’m not recovered,” but the medications help him “because of the schizophrenia and because of my wife saying that I better take it, too. I just have to keep my pills up to date.”

Several participants indicated that medication has saved his or her life. Frank stated,

If it hadn’t been for medications, I wouldn’t be sitting here talking to you. I would probably be dead either by getting into a fight with somebody... or getting shot at or killed, or me just taking a flying leap off a building. And that would be it.”

Donna shared, “Well if I didn’t take it, I would probably be dead.”

Ethel and Rebecca shared experiences around not having the appropriate medication or the appropriate dosage. Ethel prayed for a new medication and she stated,

The medication, it’s helped me and with all that I’ve been through... I’ve had a lot of fearful thoughts and in the hospitalization, I had a lot of frightening thoughts, and it’s in the past. It’s very frightening and, but now I’m all better.

Rebecca shared that she has had to advocate for her self to get appropriate medications in the following:

And I want to tell you the Depakote story. He put me on a certain amount and then he moved it up and then he moved it back and then he moved it up and up again. And I kept saying 750! 750! 750! Because I thought that was the right amount for my body. Yeah, and finally because of the blood draw, he realized that I shouldn’t be on higher and he realized I should be on 750, and he told my mom, “I hate it when the psychiatry patient is right.”

She has attended conferences about her medication and continues to work with her doctor. In the hospital, “we did the clozaril and that helped. I had all these weird ideas and it flushed out all those weird ideas, and then the clozaril helps my mind. So I have to take the clozaril for my schizophrenia.”

Rebecca shared that she has “gone off the meds a little bit.” As did Eddie who, “went off the medications once and ever since I’ve stayed on them.” Frank shared that he has “gone off of it at least five times over the past 25 years. And each time, you know, after a day being off the medication, I just go bananas.”

**Question 7: What has had the greatest impact in your recovery?** Several participants identified having social support, including the support of family and members of the S.A. group, as having the greatest impact in recovery. Rebecca listed several “friends from church” and stated, “It’s really helpful to have good friends. Good, Christian friends.” Ethel spoke to the role of religion in her recovery, “My relationship with God is what keeps me going, what keeps me from getting depressed and down and keeps my spirits up.” Eddie spoke about his wife and dog. He said, identifying supports in his recovery, “I think staying with her... I do! It would be a horrible thing if she ever left me. ...And the dog. The dog helps, too, because she does move me around. I have to take care of her.”

Schizophrenics Anonymous meetings and peers were identified as significant sources of support in recovery. Frank said that after he was discharged from the military and diagnosed with severe mental illness, he “ended up being a loner.” He identified S.A. as having

...had the greatest impact. They really, it's not group therapy... but this is the first time that's it's really helped me cope better with my illness, with my diagnosis. ...That everyone else has, outside of the facilitator, has the same problems that I have. Maybe not at the same degree of disability. ...They have this, kind of have, this ability to cover the gaps that we have with each other. If one has a problem and they can't seem to cope, another may be able to intervene.

Donna also identified S.A. as having a significant impact in her recovery. "I think S.A. My doctor told me about it, and he said, 'I want you to go to S.A.' So I called and found out where they were located. I starting thinking about being, maybe, I'm a schizophrenic." This process of identification with her disability lead her to engage in other sources of treatment and recovery support because she could then "do something about" her mental illness. Carl also identified S.A. as having a significant impact on his recovery process. He stated,

I think the people at S.A. have a lot in common with some of the members and that's a relief to me because they understand where I'm coming from and I understand where they are coming from. And I have some of the same experiences and I feel relieved by that.

**Question 8: What would be important to know about living with schizophrenia or schizoaffective disorder?** Several participants described having difficulty communicating with those who do not have a severe mental illness diagnosis. Donna shared that she doesn't "know what people don't know" and asked for understanding and forgiveness from others when she feels she has made a mistake. Carl also spoke about feeling misunderstood, "People often make the assumption or judgment

about how I'm doing and wouldn't be thinking about that and it would make me feel pretty worthless." Ethel stated that "it might be hard to explain what you need" and that "people with schizoaffective disorder, they need assistance with everyday life." She asked doctors and other treatment providers to "just listen to the patients and see what they have to say and that doctors don't understand everything." Rebecca stated, "Every little thing can set you off" and described the importance of managing stress and engaging in self-care. Eddie stated, "You don't want it."

Carl stated that schizophrenia is "a disease that's like any other disease and that it needs to be treated and there all kinds of people who have it. ... As long as they ... participate in their recovery and that they are normal just like everyone else." Frank described the universality of mental illness and psychiatric disability in the following:

Keep us safe. We are your brother, your daughter, your son, your mother, your father, your grandfather your grandmother, your sister, your friend. We may not have all the tools in the tool box, but we do work with what we have and if you see us out there, of course you know we don't wear our disability out there like a tattoo on our bodies, so the thing to remember is that things that affect you don't affect us in the same way or in the same degree. I mean everyone has a different reaction, but schizophrenics, there's a typical type of reaction. So, yeah, we're family and friends.

He also asked that others recognize that people with severe mental illness are competent, "We're not dumb. We're smart." Carl shared that he "voted for someone because she understand people who are mentally ill" and discussed the importance of advocating for the reduction of stigma of mental illness.



## Interview Themes

Themes were identified through analyzing participant responses and determining relevant and repeated ideas according to the Auerbach and Silverstein (2003) model for qualitative data analysis.

**Models of disability.** Participant responses reflected multiple views of disability.

***Morality model.*** Eddie repeatedly spoke to the morality model of disability when discussing his family reactions to his mental illness and his own views of his psychiatric disability. He stated the following,

My parents were still living but they did not accept me. And my brother doesn't accept my diagnosis because of psychiatry they don't the church doesn't go along with, and my parents don't go with my diagnosis. ...No, it's the psychiatrist aspect. They don't believe in psychiatry. Yeah it's the religious aspect. There are certain Christian beliefs that do not believe in psychiatry. ...Well they just don't understand psychiatry. And I can see the sinful nature that enters into it. And you know about the sinful nature. Even you have been taught about the sinful nature and you've known about the problems with sinful nature. And they said, it's all the sinful nature and it was a lot of it still is. I'm still a sinner.

Donna shared that her "dad was guilt and guilt. My mom was guilt and guilt" in reaction to her symptoms of mental illness.

***Medical model.*** Several participants reflected medical model views of disability. About schizophrenia, Carl stated,

It's a disease that's like any other disease... I want to say that it's a disease and with proper treatment, it can be manageable and that they can be happy and

healthy as long as they take their medicine and do the things that they were taught and participate in their recovery and that they are normal just like anyone else.

Eddie stated that he was “not recovered because I still have to take the medication.”

Participants reported that involvement in treatment typically begins with hospitalization and interaction with medical professionals. Rebecca shared, “what happened was that I had the breakdown, went to the hospital, got on the medicine, went to the hospital...went to see the doctor. Kept on seeing the doctor.” She went on to state that treatment involved, “mostly went to the doctor. So I just kept on going to doctors and changing meds around and going to hospitals and all that. All that type of stuff.”

***Social minority model.*** Participants shared their experiences of living with psychiatric disability and defining that as recovery. Carl stated, “probably one thing that I haven’t done is journal and read the blue book, the Schizophrenics Anonymous blue book, and do some other reading and just try to journal and try to follow a simple plan to keep myself in recovery.” Donna stated,

No one will tell me what they really mean. So they say when you have those thoughts you have to talk to me. My therapist will tell me you have to tell me, and tell the doctor. I have an appointment with him practically every two weeks and I told him, I have to see him, I don’t know why I just have to see him.

Frank shared,

My brother was mad at me because he said, “You’re a quitter.” And I keep telling him, “I’m not a quitter. I just don’t have that same ability I had when I was younger.” And so, but I think if I continue taking the medications right, and if I

get enough rest, and I have the right diet, I will probably be able to complete a degree, I hope.

Carl spoke about the importance of acceptance and the challenges of doing so of his mental illness. He stated,

That's a relief because sometimes when I might have trouble accepting the truth about something because if someone says something that I've never heard of before but something says, "You need to accept this, I know you don't like it but you need to accept it." Sometimes it's, I may be disappointed in what I hear because it's something that I don't want, is someone to walk away. But I know that if I help myself, then I will be able to get what I need.

**Severe mental illness integration model.** Responses related to the Onken and Slaten (2000) model of disability identity development. Given membership in the Schizophrenics Anonymous group, none of the participants demonstrated current attitudes reflecting the first three stages of this model. Reflecting the fourth stage in this model that reflects tolerance and connection, Donna stated, "I called and found out where [S.A.] was located. I started thinking about being, maybe I'm a schizophrenic." The fifth stage, immersion and resistance, is demonstrated by Frank who stated,

One person would have a buddy... have the same kind of approach to solving problems, and the same kind of diagnosis, so if one of us had a problem... we could talk to them and ... it's quicker than taking a trip to the hospital and waiting on the doctor for whenever he can see you.

Frank also demonstrated acceptance and pride, as part of stage six in this model, and stated, "S.A. [has] had the greatest impact ... it's really helped me cope better with my

illness.” Rebecca spoke about having friends and connections in both the disability and non-disability communities, which demonstrated the introspection and synthesis of the seventh stage of this model. She stated, “It’s really helpful to have good friends in the church and at S.A.”

**Recovery.** There were several factors indicated by participants that impacted recovery. Interview responses related to these factors follow below.

**Treatment.** Participants reported that treatment frequently involved frequent hospitalizations. Rebecca shared, “And I’ve been in and out of the hospital for 26 years. About 13 times for about a year and six months. Something like that. Just in an out of the hospital.” Ethel shared, “I was in and out of the hospital every year.” Donna reported that she has been “In and out for six times because they never told me what was wrong with me.” Carl stated, “And later I’ve been hospitalized and on the psych wards at local hospitals several times and I think one time I got the electric thing, the shock therapy.”

Frank shared, “Hospitals can be very helpful and I think you even said there were moments when the hospital really helped, but they can also be scary and takes you out of the environment where you’re really comfortable.” Carl discussed community treatment and said, “I’m thankful that I’m getting treated for this. ... I go to [CMHC] because it’s a good place.”

**Medication.** All participants shared that they were on medications to help manage symptoms of severe mental illness. Earl described medications as “enlightening.” Ethel shared, “The medications ... it’s helped me and with all I’ve been through I’ve seen that I need all the help that I’ve got.” Frank shared, “If it hadn’t been for medications, I wouldn’t be sitting here talking to you.”

While medications were identified as helpful, several participants reported struggling with side effects or with medical issues triggered by antipsychotic medications. Earl stated, “Right now I’m taking Lithium, which makes me drool as you can see. Awful. Embarrassing.” Frank shared, “It was really more painful. My back was stiff so they stopped doing that. They put me back on Stellazine on lower... dose. They gave me Cogentin to fight the side effects.” Donna shared that she was “put on Clozaril and that helped keep me sane, but my white blood cells went up and I couldn’t take it anymore. If I could take Clozaril, believe me, I would.”

*Medication compliance.* Several participants discussed the challenges of maintaining medication compliance. Frank shared, “I’ve gone off of it at least five times over the past 25 years and each time, you know after a day being off medication I just go bananas.” Eddie shared, “Yeah I went off of medication once and ever since I’ve stayed on them.” Rebecca shared that she faced a significant consequence of not being medication compliant, “I was messing with my medications and not taking them exactly as prescribed, and my parents didn’t know that I was doing that. So I jumped out of two-story window.”

Other participants have had difficulty with medication compliance because, as Carl shared, “People have told me that I need to take my medicine and sometimes I’ve believed something different.” Ethel stated,

The medication was a hard time getting on because they didn’t have the right medication for me. ... [My family] insisted that I always had to take my medicine even though it wasn’t working. ... I continued to take them because they were always after me even though they weren’t working.

***Control of medication and treatment.*** Participants reported having varied experiences having control or being disempowered in their own treatment. Donna described being directed in treatment, “They told me I had to, so here I am.” As previously noted, Rebecca had a psychiatrist at the hospital who did not like it “when the psychiatry patient is right” about her own care and medications. Other participants shared experiencing some ambivalence about not having control over his or her treatment. Ethel shared, “my nurse practitioner, when I saw her last in person, she agreed to decrease the medicine, but then when I talked to the pharmacist and I also called the nurse at [CMHC], she decided not to decrease it and it probably was best.” Frank shared,

Another thing that has changed since I’ve been mentally ill, it used to be that if you were destructive in society they would seclude you into a psychiatric ward but now it has to be either you’re a harm to yourself or to somebody else and that’s a good thing to some degree. But I think, too, there has to be another input, not input, there has to be another requirement on that, that if a person is disoriented that he should be hospitalized or at least be counseled in order to keep him calm.

***Coping and self-care.*** Participants shared what has helped them cope with stressors. Rebecca shared,

And so what I need to do, they need to understand what I need. I need to get my naps in. I need to get my chores in. I need to get my walk in. ... Need to tidy up more better and sometimes you just need to take time for yourself. You cannot worry about anybody else, you just have to take care of yourself or you’re going to have a breakdown.

Ethel shared that when she is unable to engage in coping strategies it impacted her mental health, “I couldn’t walk and then when I did go walk and I walked the same distance and then like that toe swelled up then I couldn’t walk and I haven’t really been walking. It’s [walking is] important for my depression.” Carl stated,

I felt like if I could just give enough and to keep myself busy and to work hard and to either get my black sash or compete in the Tour de France or something if I could then have by the time I’m done I would be too tired to have negative thoughts or to think about hurting someone or myself.

**Schizophrenics Anonymous.** Several participants noted the role that Schizophrenics Anonymous has played in treatment and recovery. Rebecca shared, I’m really having difficulty, and I’m afraid I’m going to have a breakdown and struggling with thoughts. But I think if I can get my laundry started and go to S.A. that will help my mind and I have to think about how it’s not really there. She demonstrated that S.A. helped her to manage her symptoms. Carl was speaking about his recovery and about what has kept him connected to others when he stated, “what I mean is that I think S.A. has something to do with it as well.” He stated, “I think I’m going to try to worry about connecting more with people at S.A. and I’m going to work harder to stay in recovery.”

Several participants indicated that it is the shared experience of having schizophrenia with other members of the group that benefits their recovery. Carl went on to say,

I think the people of S.A. have a lot in common with some of the members and that’s a relief to me because they understand where I’m coming from and I

understand where they are coming from and I have some of the same experiences and I feel relieved by that.

Donna shared, “I just want another schizophrenic to open up and share stuff.” Frank shared about the S.A. group members, “If one has a problem and they can’t seem to cope, another may be able to intervene.”

**Religion and spirituality.** Each participant identified as Christian and this was reflected in the repeated mention of religion as salvation or as a key to recovery.

Rebecca asked to begin the interview with a prayer and shared that she, “cried on his arm and told him what had happened with my brother and God healed me.” Ethel stated, “Well, I define recovery by having a relationship with God and salvation through God. I do not find it necessarily through my nurse practitioner because she doesn’t understand me as much as God understands me and gives me hope.” And Donna shared that, “my brother got into Scientology and that’s how he got better. But I never got better.”

**Suicide.** Five of seven participants spoke directly about suicide and shared information about past suicide attempts and friends lost to suicide. People with schizophrenia have a 50 times higher risk of attempting suicide than the general population (The Internet Mental Health Initiative, n.d.). An estimated ten to 13 percent of people with schizophrenia commit suicide and approximately 40 percent of people with schizophrenia attempt suicide. Donna stated, “These grandiose thoughts, they ruined me. They almost killed me three times.” Frank shared,

It’s a lot of stress. It is a lot of stress. But the, what the meds do, to me, is it numbs me up so I don’t feel as distressed as others. Because if I did, I probably wouldn’t be alive. I would have just gone out and do that [*made a pfft sound and*



*gestured cutting his wrists*]. As a matter of fact, I did try to do that, but it wasn't until after I was married, after my wife left.

Carl stated, "sometimes I've had the suicidal thoughts, but I know now that other people, that have shared with me, that I know it would be a very foolish idea to take my own life." Rebecca shared that a friend of hers had attempted, and later committed suicide, and that this lead her to feel "guilty" and to feel that she "couldn't think."

***Step seven: I choose to live.*** The local Schizophrenics Anonymous group added a "Step Seven" to the "Six Steps of Recovery" outlined by the larger S.A. organization (SARDAA, 2010). Rebecca shared that the group typically combined a discussion of "step seven: I choose to live and step two." Earl referenced this step when talking about what he wanted people to know about living with schizophrenia when he stated, "That guy in Michigan had said, don't, don't give up. Just don't give up. Choosing to live. Yeah, choosing to live, not give into a temporary problem."

**Work, career, and education.** Several participants referenced struggling with work, career, and education as an impact of their psychiatric disability. Four of seven participants reported having a college degree and the other three participants reported having some college education without having completed a degree. Frank shared the following:

I tried to go to school. I tried to go to college at least three or four times, at least, and no success. The last time I went to school here at [a local community college], I was sitting in class and my brain just locked up and I just couldn't get my head around what they were talking about. So I just picked up my notebook, textbook, and got my coat on, and I just walked right on out of the school and

they haven't said anything to me, and this has been what, two or three years and that was all.

Even when participants had successfully completed their education, they identified struggling to use that education. Ethel shared, "But you see, you're without a career though, and I needed to get educated. I've lost my education." Carl reported that he was actively looking for work, "I have someone helping me find work, turning in applications and looking around and that's working out." Eddie shared that his psychiatric disability had impacted his ability to maintain a job. Eddie stated, "because of my mental status I was able to get retirement from the state. I wouldn't be able to do that now. ...No it caused my retirement from the state." He went on to share that he had difficulty maintaining another job because he was not able to take off the time he needed to manage his mental illness. He stated,

Yeah and I got a job at [a charity] after that. And did that for 14 years until they said that I couldn't have any more vacations. I didn't even tell the boss that I had problems she just said that I couldn't have any more vacations. And so I quit.

## **CHAPTER 5**

### **Discussion and Conclusions**

The following discussion explores themes identified within the interview responses that are identified as facilitators of treatment seeking and compliance. The purpose of this approach and study is to honor the lived experiences of individuals living with severe mental illness to identify facilitators to treatment seeking and compliance.

#### **Demographics**

The seven participants in this study are a fairly representative sample of the local area Schizophrenics Anonymous (S.A.) group along variables of age, gender, race and ethnicity, religion and spirituality, and disability status. They were not asked about income, but did report educational achievement. Each participant reported having a range of post-secondary education from some college experience to completing a bachelor's degree, which is not representative of the larger S.A. group where several members do not report completing high school or attending college. This may impact the information presented by these participants and reflect a difference in intellectual ability and barriers experienced in attempting to obtain education from the larger population of the S.A. group. S.A. is most suitable for people with schizophrenia-spectrum disorders who have at least average verbal skills (Walsh, 1994).

These participants and the members of the S.A. group are middle aged and older, and each participant reported having a psychiatric disability for a minimum of 20 years. Approximately one million older adults have a severe mental illness (Cummings &

Kropf, 2011). These older adults have increased physical illnesses, functional impairments, cognitive deficits, and poor social connections. The results of this study indicate that having a long history of living with severe mental illness likely contributes to the participants assuming membership in a group like S.A. that requires identification as a person diagnosed with schizophrenia or a schizophrenia-spectrum disorder. Given age and length of time living with severe mental illness, participants may have different perceptions of their first experiences of severe mental health symptoms and their earlier interactions with treatment systems. This population might be impacted by how treatment is delivered. For older adults with severe mental illness there are typically formal and informal sources of treatment that provide adequate services; however, over 70 percent of individuals in this population do not receive the correct type of help for some of their needs (Cummings & Kropf, 2009). This is a particular challenge identified for older adults with severe mental illness with co-occurring medical concerns. Several participants disclosed significant health concerns that have impacted treatment for their psychiatric disabilities. Eddie shared that he had several medications for medical concerns that had to be managed carefully in conjunction with his psychopharmacological interventions.

There were more participants who were diagnosed with schizoaffective disorder than with schizophrenia in this sample. Five of seven participants reported that his or her current diagnosis was schizoaffective disorder, with the other two participants reporting a current diagnosis of schizophrenia. This may impact the results through increasing the reported incidence and impact of significant mood symptoms in addition to psychotic symptoms as participants shared their lived experiences of living with psychiatric

disability. People with schizophrenia are more symptomatic and have greater community support needs than those with schizoaffective disorder (Heinrichs, Ammari, McDermid Vaz, & Miles, 2008). However, since schizoaffective disorder is one of the schizophrenia-spectrum disorders, it falls well within the scope of this study. Additionally, several participants with a current diagnosis of schizoaffective disorder reported a history of being diagnosed with schizophrenia.

This group is highly religious and every member identified as Christian or Catholic. Additionally, several members identified as Evangelical and this is reflected in how the S.A. group meetings are typically structured. Each meeting begins and closes with prayer and members are prompted to submit prayer requests to the group. The intersection of religion and disability likely impacted participants' religiously grounded ways of viewing disability, communities of support, and worldview. This may differ from the larger population of people with severe mental illness, but is reflective of the local S.A. group. This is contrast to other S.A. group meetings in other areas. Walsh (1994) found that in the S.A. meeting in Franklin County, Ohio, discussions about religion were discouraged or stopped by the facilitator of the meeting.

### **Models of Disability**

Models of disability significantly impact the ways participants view their own psychiatric disabilities. Fitzgerald (2010) found that being aware of psychiatric disability and trying to make sense of a personal experience of psychiatric disability was found in people who were also engaged in treatment with health services. The morality and medical models were reflected most often in the participant interview responses.

**Morality model.** The morality model continues to be a prevalent framework for understanding psychiatric disability among the participants interviewed. As suggested by Olkin (2002), the morality model was the most common frame of understanding disability. Participants described shame and guilt they personally held related to their psychiatric disabilities. Eddie repeatedly referred to his “sinful nature” as a way of explaining and understanding the cause of his mental illness, and how he blames himself for his continued struggles with mental illness. Eddie’s parents did not “believe in psychiatry” because of religious beliefs and he experienced this as a rejection of him by his parents. This reflects that disability is understood as a defect caused by a moral lapse or sins (Olkin, 2002). The morality model also suggests that disability comes from a failure from the family. Donna’s parents were “guilt and guilt” upon learning about her and her brother’s psychiatric disabilities. This guilt reflects the responsibility felt and the associated shame attached to psychiatric illness.

Just as disability comes from sin, healing comes from prayer. As noted, the participants in this research identified as highly religious. Rebecca, Ethel, and Carl made statements relating to being saved through prayer and a personal relationship with God. Ethel noted that her relationship with God and her prayers, not her nurse practitioner, provided to her the correct medications. The results of this study indicate that prayer can be seen as treatment seeking. It was through prayer that Ethel believed she was able to get the appropriate medication. In this way, prayer was a facilitator for her treatment compliance.

Donna shared that her brother “got better” after becoming involved in scientology – a religion that views psychiatry and psychology as “demonic competitors” (Wright,

2011, “The many discrepancies,” para. 9). This religion represents a rejection of the medical model of psychiatric disability by finding “cure” only through religious practices. So while Donna identified scientology as a facilitator for her brother, it did not benefit her at all.

While a relationship with God was identified as important in recovery and cure, participants did not say that having a psychiatric disability reflected a special connection with God or the spiritual realm, which is how mental illness is viewed in some other cultures (Olkin, 2002). This reflects the ableism and stigma present in the dominant culture in which these participants live where psychiatric disability is viewed as dangerous, uncontrolled, and unpredictable (Appleby et al., 2001). There was some support for disability being a challenge to be an inspiration to others (Olkin, 2002). Engaging in prayer and faith-practices serves as a way for Ethel and Rebecca to connect with others and engage in recovery. Ethel identified becoming involved in her faith-community as a key facilitator in her recovery and engagement in treatment.

**Medical model.** The medical model views disability as pathology and as a defect or failure of the body (Olkin, 2002). This model is also known as the “normalcy model” because of the emphasis on treatment being on eliminating the disability or the symptoms of disability. Several participants described views stemming from the medical model, especially when defining recovery. Carl identified his mental illness as a “disease” that could be “treated.” Frank spoke about wanting to be “normal” and “appropriate.”

Eddie shared that he feels that he is “not recovered because I still have to take the medication.” This reflects an older definition of recovery that allows for recovery to only be present when all symptoms are gone and health is regained (Resnick et al., 2005). In

spite of no longer hearing voices and experiencing fewer symptoms, Eddie continues to depend on medication for symptom alleviation and therefore does not view the disability as eliminated and himself as “cured.” This is reflected in the medical model view that people with severe mental illness remain “sick” even when functioning well with psychiatric disability (Bassman, 2005). Participants engaged in medical interventions that seek to eliminate symptomology of psychiatric disability while concurrently engaged in activities like Schizophrenics Anonymous that define recovery as not periods of health, but as learning to live with disability (SARDAA, 2010). This is reflected in Donna’s identification as a “paranoid schizophrenic” and in her active participation in the S.A. group, while engaging in medical intervention like, “taking the medicine, and if you’ve got these thoughts, tell your doctor” as part of her recovery.

For the participants, their informants about psychiatric disability were largely medical professionals. The first contact between health care professionals and the person experiencing an initial episode of psychosis impacts the individual’s attitude toward and acceptance of treatment (Abdel-Baki, Ouellet-Plamondon, & Malla, 2012). Participants learned about their diagnoses from medical professionals and what that diagnosis was and information about the diagnosis frequently depended upon whom they were meeting. The diagnostic criterion for schizophrenia has changed repeatedly over the last 100 years, and will change again with the release of the *DSM-V* to include less attention to reality distortion and increased attention to negative symptoms as symptoms for diagnosing schizophrenia (Keller, Fischer, & Carpenter, 2011). Earl shared that he needed “to study it more to see what kind of an update it is on schizophrenia because schizophrenia in



those days was an altogether different thing that it is today.” He was reflecting of the changing meaning of his diagnosis.

Donna discovered her diagnosis because she saw her medical information. Frank shared, that he has “a new psychiatrist, so she’s working on her diagnosis.” This reflects a lack of control and personal participation in determining diagnosis and labeling psychiatric disability. Several participants shared that their diagnoses had been changed multiple times. Earl was confused about his current diagnosis and was not sure about the differences between schizophrenia and schizoaffective disorder. Eddie was not sure about his diagnosis. He stated, “Current diagnosis? I don’t know. He hasn’t told me.” He then looked at his notes from his appointments with his psychiatrist and identified that he had schizophrenia. Each participant identified having a psychiatric disability, the nature of that disability as determined by the *DSM-IV-TR* and his or her medical informants was not always clear. Once diagnosis became clear or was understood, the participant was more likely to seek and engage voluntarily in treatment.

Rebecca shared that she learned more about her own diagnosis of schizoaffective disorder, bipolar type, and how that differs from other diagnoses through a S.A. meeting. She stated, “The girl who came before you... she went through different diagnoses from the book [the *DSM-IV-TR*] and wrote down notes and talked about them one meeting like that. ...She discussed bipolar and schizophrenia and stuff like that.” She learned about differential diagnosis from a non-medical informant. Other participants shared that they read about their symptoms and diagnoses. So while medical informants diagnose, they were not observed to share information about the process of diagnosis, what the diagnosis means, and how the experiences of the person are labeled as symptoms of a disorder.

Both Carl and Earl were unclear about what schizophrenia was when initially diagnosed. They believed schizophrenia was multiple personality disorder and neither participant felt that it was an accurate diagnosis. After learning more about the symptoms of schizophrenia, each participant felt that it was an accurate diagnosis and engaged in treatment.

**Social minority model.** Participants demonstrated some support for viewing psychiatric disability through the social minority model. The findings of this study, and limited discussion in the literature, indicate that this model of disability has not been applied to psychiatric disability as broadly as it has been discussed in relation to physical disabilities. Proponents of the social minority model work toward political, economic, and social change (Olkin, 2002). The larger Schizophrenics Anonymous organization has a mission to advocate for individuals with schizophrenia-spectrum disorders and to reduce stigma (SARDAA, 2008, November 27). Carl shared that he was interested in reducing stigma and voted for political candidates that supported mental health reform.

Engaging in social justice and anti-stigma work may improve self-esteem (Mashiach-Eizenberg, Hasson-Ohayon, Yanos, Lysaker, & Roe, 2013, April 6). Frank shared that he wanted people without psychiatric disability to know that people with severe mental illness are “not dumb. We’re smart.” He asked to be recognized as competent and to not have others assume incompetence because of his disability. This reflected a social minority model of understanding disability. The findings of this study are limited in identifying facilitators within the social minority model of disability because the lived experiences of the participants rarely reflected this model.

## **Severe Mental Illness Integration Model**

Participants reflected different, later stages of Onken and Slaten's (2000) model of disability identity development. The findings of this study indicate that identification with later stages of disability identity development around psychiatric disability facilitates treatment seeking and compliance. As Donna began to identify as a "schizophrenic" she began voluntarily seek treatment. She shared that this happened when she was in her 50s, which followed an initial psychiatric disability diagnosis when she was in her 20s. Participation in S.A. positively impacted her in aiding her in developing an identity around her psychiatric disability and then motivating her to engage in treatment. She sees her doctor and therapist regularly and considers this engagement in treatment a part of her recovery.

Frank shared that he had sought treatment through his disability community. This reflects identification in the immersion and resistance state of disability identity development (Onken & Slaten, 2000). Identification with this stage facilitates treatment seeking; however, the treatment may be outside the medically established and supported treatment modalities and reflect an interest in retreating from ableist society.

Reflecting the sixth stage of Onken and Slaten's (2000) model for positive disability identity with severe mental illness, several participants expressed acceptance and pride in their participation in the S.A. group and expressed respect and caring for other group members. Frank, Donna, Earl, Eddie, and Carl all identified S.A. group members as sources of social support. Several participants identified S.A. as a source of support in recovery. Donna shared that S.A. was an important part of her treatment and to talk about her concerns "with other schizophrenics, to talk about what it is I'm feeling

and how I'm feeling. ...And I didn't have that when I came to S.A. the first time." The relationship with other people with schizophrenia is identified as a facilitator for her recovery and engagement in treatment.

In the final stage of Onken and Slaten's (2000) model of disability identity development, the person demonstrates introspection and synthesis and is able to connect to people in both the disability and able-bodied communities. Reflecting this, Frank spoke about the universality of the disability experience, particularly of mental illness.

We are your brother, your daughter, your son, your mother, your father, your grandfather, your grandmother, your sister, your friend. We may not have all the tools in the tool box, but we do work with what we have and if you see us out there, of course you know we don't wear our disability out there like a tattoo on our bodies, so the thing to remember is that things that affect you don't affect us in the same way or in the same degree. I mean everyone has a different reaction, but schizophrenics, there's a typical type of reaction. So yeah we're family and friends.

Frank indicated that he would like to join with the able-bodied community while maintaining his identity as a person with severe mental illness.

**Identity development and facilitators of treatment.** The findings of this study indicate that as participants identified with later stages of the Onken and Slaten (2000) model, they identified more facilitators to treatment seeking and compliance. Rebecca identified friends that are not part of the disability community as important facilitators in her treatment compliance. When she had stopped taking her medications at one time, it was a friend from church that she trusted that helped her begin taking her medications

again. By identifying able-bodied allies, while remaining connected with the disability community, Rebecca was demonstrating introspection and synthesis, the final stage of disability identity development as proposed by Onken and Slaten (2000).

Donna shared that through engaging in S.A. she thought, “Maybe I’m a schizophrenic.” She was first diagnosed with schizophrenia when she was in her 20s and it was not until she became involved with a disability community, when she was in her 50s, that she developed an identity around her diagnosis. This mirrors the tolerance and connections stage proposed by the Onken and Slaten (2000) model, and it was through this process that Donna began to voluntarily seek treatment and build a social support system through a disability community. Frank demonstrated that as he engaged in disability identity development, he began to connect with peers through S.A. and recognize the universality of mental illness, which helped him to connect with his family. When he was initially diagnosed, Frank shared that he struggled to remain connected with his family because, “it just didn’t seem like I was able to because of this diagnosis and the way my behavior was.”

## **Recovery**

Recovery from severe mental illness has been defined as the personal process of moving out of illness and into health and wellness (Hendryx, Green, & Perrin, 2009). Rebecca shared that her father has said that she has “triumphed over mental illness.” This view of recovery indicates that there is a fixed point of health and wellness that means the person is recovered. In contrast, the lived experiences of the participants indicate that recovery is an on-going process of living with symptoms and learning to cope effectively.

**Personal definitions of recovery.** Recovery has a changing definition and the process should be initiated by the person with severe mental illness and developed through the establishment of a meaningful life and an affirmation of identity (Lysaker et al., 2010; Andreson et al., 2003). The findings of the present study indicate that personal definitions of recovery can facilitate treatment seeking and compliance behaviors. Carl shared that recovery for him means that his “life is manageable and things are not out of control and I’m able to get through.” He shared that he works towards his recovery through seeking treatment by working with people at the CMHC, taking his medications, attending S.A. groups, and engaging in prayer. Frank also shared that recovery included having symptoms, but managing them effectively. He stated,

Recovery for me would be that, instead of getting overly panicked, overly nervous, that that nervousness would only last for, at the most, five to ten minutes, at the most. Normal for me would be to be able to enjoy TV programs that I really like to watch. Being able to walk outside, down the street, without thinking that someone is talking about me.

His ability to feel that he was engaging in recovery prompted him to seek treatment when he struggled. He shared that he sought treatment at the VA and engaged with multiple providers there. From the perspective of people with severe mental illness recovery comes from positive changes in attitudes, feelings, perceptions, beliefs, goals, and roles (Spaniol et al., 1999). These positive changes are determined by the individual.

Ethel defined recovery as not “experiencing more mood stuff. ...I think I got the right medicine to take care of that.” Her definition of recovery included the need to maintain treatment and medication compliance because it was helpful and supportive of

her recovery process. Rebecca also identified medications as an important part of her recovery. She shared that she is “recovering” and that it involves vacations that are “bright spots” for her and she would not be able to go on vacation if she was not maintaining her treatment compliance. Her personal definition of recovery facilitated her treatment seeking and compliance.

Rebecca shared that she felt relief when she learned more about schizophrenia and could identify her symptoms and experience in the description of it in her high school health class. Central to the recovery movement is the importance of psycho-education about mental illness and various treatment options (Davidson, 2010). Donna also identified learning more about her severe mental illness as an important part of her recovery. She stated,

The greatest thing that helped me feel better was to know that I was a schizophrenic and to do something about it. So I did. I did something about it. ...I went to the hospital and found a good doctor ...and then I ended up back here and I never felt better in my life.

When she learned more about schizophrenia, she began to identify more as a person with schizophrenia and then began to voluntarily seek and engage in treatment.

### **Religion and Spirituality**

The findings of this study indicate that religion and spirituality are an important source of support within recovery; however, the participants did not necessarily see this as a facilitator for treatment seeking and compliance. People with schizophrenia and who have a higher religious affiliation have demonstrated less preference for psychiatric treatment (Huang, Shang, Shieh, Lin, & Su, 2011). While religious affiliation may

decrease treatment seeking, religiousness appears to have a positive impact on the quality of life of older adults with schizophrenia (Cohen, Jiminez, & Mittal, 2010). Ethel demonstrated this difference in speaking about her relationship with God and diminishing the role of her medical provider in her recovery. Donna and Eddie mentioned family members having religious beliefs that did not support psychiatry and medicine as a path to recovery. Mohr et al. (2012) found that religion sometimes conflicted with psychiatric treatment.

Previous research has primarily focused on religious delusions as symptomatic of schizophrenia-spectrum disorders and there has been limited research into the role of religion in coping (Nolan et al., 2012). Positive religious coping has been associated with higher quality of life, while negative religious coping is associated with lower quality of life. This study supports this finding as reflected in Donna's disclosure about her suicide attempts. She thought she had "hurt Jesus" and made three suicide attempts because of this negatively valenced religious belief. At times, Donna shared that she would choose not to come to group because the meeting was focused on religion. This is a shared experience with a group in Franklin County, Ohio where there were several occasions when a member would stop attending meetings because of the religious preoccupations and preaching in the group by some other members (Walsh, 1994). In contrast, Ethel identified positive religious coping through prayer and connection to God and shared that this improved her quality of life. Carl also shared that his relationship with God has kept him from harming himself and feels positively about religion. Mohr et al. (2012) found that 87 percent of people with schizophrenia or schizoaffective disorder experience religion as helpful (supported a positive sense of self and positive coping with psychiatric



disability), and 13 per cent reported that religion was harm (a source of despair and suffering).

This study supports that being connected to a faith community has a positive impact on recovery. Rebecca, Eddie, Ethel, Carl, and Earl each identified fellow church members as significant sources of social support. Seeking support through faith-based communities supported these participants in their recovery. This is separate from medical and psychological supports in recovery. Weisman de Mamani, Tuchman, and Duarte (2010) found that integrating religious and spirituality elements into treatment for individuals with severe mental illness is beneficial for those individuals. Increased awareness of the importance of positive religious coping in the lives of people living with severe mental illness may lead to more culturally competent care (Nolan et al., 2012). Religion may become a facilitator for treatment seeking and compliance if competently integrated into treatment. The risk is that ignoring religion and spirituality in treatment can result in invalidation of the individual with severe mental illness (Smith & Suto, 2012). The sometimes conflict between religion and psychiatric treatment underlines the importance of appropriately integrating religion into treatment as a facilitator for treatment seeking and compliance (Mohr et al., 2012).

### **Sources of Social Support**

Participants identified multiple sources of social support that facilitated treatment seeking and compliance.

**Social network.** The results of this study suggest that social support can be an important facilitator for treatment seeking and compliance. Rebecca reached out to a

friend when thinking about stopping part of her treatment and becoming medication noncompliant. She shared,

[I talked to my] friend [Sam]... I didn't trust anyone but her, and I said, "[Sam], I want to go off my medicine." And she says, "...if you go off..." and I had already gone off of it for a little while, a few days, but it wasn't that toxic to go off of it for a few days... she said, "...if you go off the medicine, you'll go right to [a hospital]." So I decided, okay, I'm not going to go off the medicine. ...And then I called her and said, "I'm staying on the medicine." And she says that was adult and stuff.

In this example, Rebecca's social support system played a key role in her re-engaging with treatment and maintaining medication compliance. As demonstrated in Rebecca's experience, social support has been found to be a positive complement to treatment, not as a substitute for formal treatment (Tsai, Desai, & Rosenheck, 2011).

Hendryx et al. (2009) found that social support and network size and engagement in more activities is related to increased experiences of recovery in individuals with severe mental illness. Identifying and participating in meaningful activities contributes to recovery. This is supported by findings in this study, which indicate that participants identify attending church and S.A. meetings as key sources of social support and social activity engagement. Treatment can be facilitated by increasing social support networks and engagement in meaningful social activities (Tsai et al., 2011; Hendryx et al., 2009). Donna was referred to S.A. meetings by her psychiatrist and through these meetings she shared that she learned more about her disability status and then began to participate voluntarily in her own treatment.

Participants in this study also shared that they struggled socially and that this had a negative impact on their self-esteem and caused distress. Franks shared that he “ended up being a loner.” Carl shared that he struggled to connect with others because the symptoms of his mental illness have interfered with his attempts to socialize with others. He talked about not pursuing a romantic interest because “something told me, ‘Don’t do that.’ And I regret a little bit.” Earl shared that he felt rejected by his social support system after he was diagnosed with severe mental illness. He stated, “The friends I had, peer groups in the past... you know they quit hanging out with me. ... You know, I just didn’t hear from them anymore.” Positive social support that complements treatment appears to be a significant facilitator of treatment seeking and compliance. Negative social support or perceived rejection from social support continue to impact Carl and Earl, and did not facilitate engagement in treatment. A lack of social support networks does not necessarily lead to increased dependence on professional support and treatment seeking and compliance (Tsai et al., 2011).

**Family support.** All participants shared that they have significant family support. Rowe (2012) suggested that family members are often under an obligation to care for their relatives with severe mental illness and that this comes from filial bonds and perceived obligation. Rebecca, Donna, Frank, and Carl all shared that their families have visited them in the hospital. Eddie shared that his relationship with his wife has had the greatest impact on his recovery. Positive family relationships, and engaging in activities with family, supports positive self-esteem in people with severe mental illness and increased functioning (Van Dongen, 1998). Frank shared that his family “said to me,

they said, that they loved me and they would do anything for me to make me better. They supported me. They didn't ostracize me from the family."

The findings of this study indicate that family can serve a supportive role in treatment compliance. Ethel shared that her family insisted that she take her medications, even when she felt they were not working, but their insistence served as a facilitator for her treatment compliance. Eddie said that his wife helps him organize his medications in order to maintain his medication compliance.

Both Donna and Earl shared that they became involved in treatment because of their parents. Earl's mother suggested that he see a trusted church member and from there he was referred on to medical professionals and was involuntarily hospitalized. Donna's parents pursued a mental inquest warrant for her, which lead to her first hospitalization and initial engagement in treatment. This was not voluntary and Donna shared that she did not voluntarily seek treatment for her psychiatric disability for several decades, but was typically involuntarily mandated to treatment. People who experience mandated treatment are more likely to identify barriers in treatment (Van Dorn, Elbogen, Redlich, Swanson, Swartz, & Mustillo, 2006). Family and social support can moderate these barriers to treatment that arise from mandated treatment. The findings of this study and research from Van Dorn et al. (2006) indicate that family support can be a facilitator for treatment seeking and compliance, even when that treatment is mandated.

Family members also aided participants in making decisions about treatment. Frank shared that his mother and brother refused to allow his psychiatrist to prescribe "electroshock therapy" and the psychiatrist then decided to prescribe different medications that helped Frank manage his symptoms. Rebecca's mother encouraged her

to remain on Clozaril and to advocate for herself with her doctor about her medication. Rowe (2012) found that family members that provide care and support in making treatment decisions experience barriers in providing care and support. These barriers include medical staff attitudes, inadequate communication between treatment providers and family, and misdirected services that did not help to meet the needs of the family or the individual with severe mental illness. While family support has been identified as a facilitator of treatment seeking and compliance through this study, the efficacy of family support as a facilitator is moderated by the perceived helpfulness of the treatment provider and treatment itself.

**Schizophrenics Anonymous.** The findings of this study indicate the participants identify participation in S.A. and engagement in S.A. meetings as a facilitator of treatment and recovery. Rebecca shared that going “to S.A., that will help my mind.” Davidson et al. (1999) found that consumer-run services, like S.A., work to improve symptoms, promote larger social networks, and improve quality of life. Walsh (1994) found that S.A. serves as an important source of support. Frank shared that S.A. has had the “greatest impact” in his recovery and provided a new way to engage in treatment. Donna shared that S.A. helped her develop an identity around having schizophrenia. Beeble and Salem (2009) found that S.A. supported recovery through four phases: mourning and grief, awareness and recognition, redefinition and transformation, and enhanced well-being and quality of life.

Donna and Carl shared that they read the “blue book” from SARDAA (2010) that presents the “Six Steps of Recovery” as a way to engage in recovery. Carl shared that the

“Six Steps” and the additional seventh step – “I choose to live” – that this group created have positively impacted his recovery. He stated,

I think all the seven steps have to do with it. And I think the people at S.A. have a lot in common with some of the members and that’s a relief to me because they understand where I’m coming from and I understand where they are coming from and I have some of the same experiences and I feel relieved by that.

It is the connection and relationship with other S.A. members that prompts Carl to feel “relieved.” Carl and Donna both shared that having other people in the group share about their experience and offer support to one another was a facilitator of recovery. Eddie shared that “some of my friends might know but only the S.A. people know” about his mental health status and diagnosis. Better current mental health is associated with being open about diagnosis and feeling less isolated (Pandya, Bresee, Duckworth, Gay, & Fitzpatrick, 2011).

Walsh (1994) identified nine common discussion topics in S.A. groups: coping with symptoms of schizophrenia, general sharing about the previous week, coping with depression, actions and side effects of medications, family relationships, vocational concerns, educational topics, other relationships, and dealing with mental health professionals. Discussion of these issues and identifying shared experiences increases cohesion in the group. This cohesion as identified by the participants in the present study is a facilitator for treatment seeking and compliance. S.A. is most suitable for people with severe mental illness that have fairly conventional views about treatment for schizophrenia (Walsh, 1994). This may contribute to the identification of S.A. as a facilitator of treatment seeking and compliance by the participants in the present study.

Frank shared that having another person with a psychiatric disability helped him cope at times when he was struggling. He shared that he had support for going to the hospital when needed and support in coping more effectively at times when he otherwise would have gone to the hospital.

### **Trust**

Several participants indicated that trust is an important facilitator in treatment seeking and compliance. Frank identified having “problems with trust” and that this kept him from seeking help at times because he did not “know what the right thing is all the time.” A lack of trust can be a barrier for treatment seeking and compliance. Chadda, Agarwal, Singh, and Raheja (2001) found that trust was an important factor in help and treatment seeking. Donna shared that she tries “to trust” and has found a positive and trusting relationship with her therapist. This trust in her relationships with her therapist and her doctor lead her to seek frequent appointments and to reach out for help when struggling with symptoms. Rebecca shared that she had difficulty “knowing who to trust.” She identified trusting her friend and her mother when they told her to maintain medication and treatment compliance. When struggling with symptoms or confused about what to do, participants identified that relationships with trusted others were a facilitator for treatment seeking and compliance.

### **Communication with Treatment Providers**

Participants identified having trouble communicating their needs to mental health professionals throughout their histories of treatment. Rebecca’s doctor did not respond to her when she expressed that she felt the dosage she needed for one of her medications needed to change. After seeing lab information, the doctor “realized I should be on 750,

and he told my mom, ‘I hate it when the psychiatrist patient is right.’” Rebecca experienced the actions and side effects of her medications personally, but the psychiatrist discounted her knowledge about herself and her lived experience. She continued to be involved in treatment partly because she was hospitalized at the time, but she experiences negative feelings towards her doctors at times because she does not feel heard. Ethel stated that she hopes people without severe mental illness and treatment providers “listen to the patients and see what they have to say and that doctors don’t understand everything.”

The findings of this study indicate that feeling heard and assisted in effective ways by treatment providers is a facilitator of treatment seeking and compliance. Ethel stated, “It might be hard to explain what you need” to others, but that she needed “assistance with everyday life” at times. She continued to engage in treatment by seeing her nurse practitioner in order to get her medications. Donna shared that she frequently meets with her treatment providers and maintains her treatment compliance because she feels heard by her therapist and psychiatrist. She shared that she has “these thoughts and sometimes they are real to me, and my therapist told me to pretend she’s there telling me that it’s not all about me.” Frank and Carl have access to multidisciplinary teams and through having different needs met, they continue to engage in treatment. Carl shared that he worked with someone through the CMHC that helped him look for work. Through having access to these services, participants identified being more willing to maintain treatment compliance since their needs are being met. Frank stated that he has “the whole nine yards now” in treatment.



## **Coping and Self-Care**

The findings of the present study indicate that coping and health self-care are facilitators for treatment seeking and compliance. Several participants identified taking care of themselves as important. Rebecca shared that doing chores, taking naps, and going for walks are her priorities for taking care of herself and maintaining her mental health. Rebecca identified living in an environment and having social and family support that recognizes the importance of these activities to her as a facilitator for her treatment seeking and compliance. Ethel also identified walking as an important coping strategy for “working with depression, besides schizophrenia.” Engaging in these coping skills is a way to seek treatment and maintain compliance. For Carl, coping strategies are a way to minimize “negative thoughts or to [not] think about hurting someone or myself.” Frank shared that taking his medications correctly and maintaining his treatment compliance is a part of coping and self-care.

## **Work, Career, and Education**

The findings of the present study indicate that work, career, and education can be facilitators for engaging in treatment and compliance. Eddie had a career as an accountant and in order to maintain this career he sought treatment when he first experienced symptoms. Carl worked with his treatment providers to find work. This desire to find work and the availability of the services at his CMHC to help him do so facilitated his treatment seeking and compliance.

Treatment can have a negative impact on work, career, and education. Ethel shared,

But you see, you're without a career though, and I needed to get educated. I've lost my education. All the medicine just wiped out all my memory and the education that I had and it's it seems like a big waste.

Eddie and Frank were forced into retirement because of symptoms of severe mental illness. Frank had difficulty attending school and completing a degree because of his symptoms. Padron (2006) identified the need for increased understanding and support for students with psychiatric disabilities as a facilitator for engagement in post-secondary education. Students with psychiatric disabilities must cope with symptoms, receiving life altering diagnoses, and learning to live with diagnosis and treatment. Appropriate and readily available services and support for these students can serve as a facilitator for treatment seeking and compliance. Participants in the present study identified more barriers to education, work, and career than facilitators.

### **Limitations and Implications for Future Research**

There were several limitations of the present study that should be considered in future research pertaining to identifying facilitators to treatment seeking and compliance. The sample size was small and participants were drawn only from one S.A. group. The primary researcher was only able to recruit seven volunteer participants, which did not meet the original research goal of completing interviews with eight to ten participants. There are over two million people living with schizophrenia in the United States and more than 150 groups meeting in 31 states in the United States and in Australia, Brazil, Canada, Mexico, France, India, and Venezuela (SARDAA, 2010). The lived experiences shared by participants may not represent the experience of living with schizophrenia or a schizophrenia-spectrum disorder for people living elsewhere in the United States and the

world. Similarly, how the S.A. group operates within this local sample may not be representative of other S.A. groups throughout the world.

Due to the small sample size the generalizability of the current study is questionable. The gender, age, and racial and ethnic diversity represented the local S.A. group. The educational level, SES, and religion and spirituality diversity of the participants was limited, though did represent the diversity variables present in the local S.A. group. It is possible that the current results are not generalizable to the larger population of people living with schizophrenia or a schizophrenia-spectrum disorder. In addition, participants were all recruited from the local S.A. group and findings of the present study that indicated that S.A. was an important facilitator of treatment seeking and compliance were likely impacted by participant membership in that group. Future research focused on identifying facilitators of treatment seeking and compliance may benefit from recruiting a larger sample of participants from a diverse geographic area and from a diverse number of treatment settings, and participants who are not involved in treatment.

The findings of this study indicate that disability identity development may be an important facilitator for treatment seeking and compliance and improve quality of life. Future implications of this study for clinical practice suggest that it may be important for social support systems, treatment providers, family members, and all others involved in the treatment and care of people with severe mental illness to receive training in disability identity models. Future research may focus on the impact of this training on the lived experience of people with schizophrenia and the development of positive disability identity around severe mental illness.

**Relationship of primary researcher with S.A. group.** Another possible limitation of the present study is that the primary researcher knows these S.A. members personally. She served as the facilitator of the group for approximately one year before the interviews occurred and left within three months after the interviews were complete. The information provided by participants about the importance of S.A. in their recovery and treatment may have been exaggerated because of the role of the primary researcher as the group facilitator. This may limit the generalizability of the findings of this study.

The role of mental health professionals' involvement in consumer-driven group is controversial; however, group facilitators gain more credibility and acceptance by S.A. group members by staying with the group over an extended amount of time, providing support to the process of the group, and through encouraging group members to utilize coping skills and resources from everyday life rather than referring group members to formal treatment services (Walsh, 1994). The primary researcher's relationship with the S.A. group may have facilitated discussion and trust between participants and the primary researcher, which may have increased the participants' level of self-disclosure about his or her lived experience.

**Interviews.** A limitation of the interviews conducted with participants was the limited number of questions asked and the limitation on the range of elements addressed through these questions. There are an infinite number of questions, subjects, and possible facilitators to treatment seeking and compliance that might contribute to the research on identifying such factors. The interview questions developed for the present study were open-ended questions and were intended to invite more disclosure and discussion within the interview. Future research would benefit from asking more direct questions about

facilitators of treatment seeking and compliance already identified, in addition to questions that are open-ended to continue to invite the identification of other facilitators.

## **CHAPTER 6**

### **Summary**

There are many cultural assumptions about psychiatric disability and the experience of living with schizophrenia and schizophrenia-spectrum disorders. There is little research literature that looks to the lived experience of people with severe mental illness to inform treatment and clinical interventions. Though there has been a shift towards the social minority model of disability to understand psychiatric disability, there remains a need to improve the ways that society views, treats, and understands people with severe mental illness. The present study attempted to identify facilitators of treatment seeking and compliance through the participant's lived experience.

There are several clinical implications of the present study. Treatment providers should be aware of the importance of social and family supports as key facilitators to treatment seeking and compliance for people with severe mental illness. Professionals engaging people with severe mental illness in treatment would benefit from recognizing the importance of social support and that this social support can work as a complement to treatment, not necessarily as a replacement (Tsai et al., 2011).

Results of the present study and other reviewed literature highlight the importance of trust, coping and self-care, and religion and spirituality as facilitators to treatment seeking and compliance in people with severe mental illness. Religion and spirituality were identified as especially important. The literature suggests that when religion and spirituality are appropriately integrated in treatment this can lead to more culturally

competent treatment and care (Nolan et al., 2012). Professional treatment providers should also recognize the importance of building trust in relationships with people with severe mental illness. Participants in this study shared that they had difficulty building trust in relationships and the literature indicates that trust is an important contributor in promoting help seeking behavior (Chadda et al., 2001).

It is important that future research continue to explore and identify facilitators for treatment seeking and compliance. This research would benefit from remaining consistent with PAR and use the voices of people diagnosed and living with severe mental illness to inform all stages of research development and execution. Continuing to contribute to this area of knowledge will benefit treatment providers and people with severe mental illness to increase the voluntary compliance in treatment of severe mental illness.

## **Appendix A**

### **Interview Questions**

1. When and how did you know you had schizophrenia or schizoaffective disorder?
2. What do you think about your diagnosis? Do you agree with your diagnosis?
3. How did your family and friends react to your diagnosis?
4. How did you get involved in treatment?
5. How do you define recovery?
6. What role does medication play in your recovery?
7. What has had the greatest impact in your recovery?
8. What would be important to know about living with schizophrenia or schizoaffective disorder?



## **Appendix B**

### **Interview Protocol**

Thank you for your participation in this study. Your responses are appreciated. The purpose of this interview is to gain a better understanding about what kind of questions clinicians should be asking people diagnosed with schizophrenia or schizoaffective disorder to increase treatment seeking and compliance. I am exploring the relationship between forming a disability identity around the diagnosis of schizophrenia and schizoaffective disorder and treatment seeking and compliance.

While a great deal of research has been done and is being done on schizophrenia and schizoaffective disorder, the voices of people living with these diagnoses have not always been acknowledged and heard. I am here to ask you some questions about your experience of living with schizophrenia or schizoaffective disorder.

Anything you tell me today will be kept confidential, in any way that it is used. This means that your name will not be connected to anything that you have said or provided to me. You do not have to answer any questions that you do not want to, and you are allowed to end the interview at any time. There are eight questions and one questionnaire and this interview should take about an hour. There are no “right” or “wrong” answers and please be as honest as possible.

Do you have any questions?

## **Appendix C**

### **Consent Form**

The relationship between disability identity formation in people with severe mental illness and treatment seeking and compliance:  
A participatory action research study

This consent form is to certify my willingness to participate in this research study.

Kimberly Sommers, a doctoral student in the School of Professional Psychology at Wright State University in Dayton, OH, is conducting a research study to determine how to approach the issue of how disability identity formation with regard to psychiatric disorder impacts treatment seeking and compliance. I am being asked to participate in this study because I have a history of severe mental illness.

My participation in this study will involve engaging in a one hour, open-ended interview with the primary investigator, Kimberly Sommers. This interview will be audio taped. Following the interview, the tape will be transcribed such that all identifying information about me will be removed, and the tape will be destroyed.

During the course of the interview, I will be asked to answer questions about my psychiatric disability. I will also be asked some questions about my demographics, such as my age, ethnicity, and diagnosis. This information will not be used in any way to identify me. Information that I provide will be kept strictly confidential and all responses I provide will not be associated with my identity in any way.

It is possible that my participation in this study may elicit mild psychological distress related to the disclosure of information of a personal and potentially difficult nature. If I experience psychological distress that is intolerable or beyond what I expect, I may choose to contact a mental health professional to address my concerns by asking my primary care physician for a referral.

There will be no direct benefit to me from participating in this study. However, the information that I provide may help health professionals to better understand the experiences of severe mental illness and the impact of treatment on recovery. My participation or non-participation in this study will in no way impact my standing with Schizophrenics Anonymous.

Any information about me obtained from this study will be kept strictly confidential and I will not be identified in any report or publication. participation in this research is voluntary. I am free to decline to be in this study, or to withdraw from it at any point. Further, I can choose not to answer any question during the course of the interview, for any reason, with no repercussions.

If I have questions about this research study, I can contact the researcher, Kimberly Sommers at 808-349-7863 or [sommers.13@wright.edu](mailto:sommers.13@wright.edu), or Dr. Julie Williams, faculty advisor, at 937-775-3407 or [julie.williams@wright.edu](mailto:julie.williams@wright.edu). If I have general questions about giving consent or my rights as a research participant, I can call the Wright State University Institutional Review Board at 937-775-4462. If I would like a copy of the group (not individual) results of this study, I can contact Kimberly Sommers at the email address provided above.

I have read and understand the above statements, and by signing on the line below, I indicate my consent to participate in this study.

---

Signature

---

Date

---

Witness Signature

---

Date

## **Appendix D**

### **Schizophrenics Anonymous Recruitment Letter**

TO: Schizophrenics Anonymous

Do you have a diagnosis of schizophrenia or schizoaffective disorder?

Would you be willing to discuss your experience of living with that diagnosis?

If so, please consider participating in the following research study:

Kimberly Sommers, a doctoral student in the School of Professional Psychology at Wright State University in Dayton, Ohio, is conducting a research study on the relationship between disability identity formation in people with severe mental illness and its impact on treatment seeking and compliance. This research is being conducted under the supervision and advisement of Dr. Julie Williams, faculty advisor.

The first 8-10 eligible volunteers will be asked to complete a brief demographic information questionnaire and engage in an in-person interview with Kimberly Sommers. It is estimated that the entire process will take approximately one hour. If you are willing to participate, please contact Kimberly Sommers at (808) 349-7863 or at [sommers.13@wright.edu](mailto:sommers.13@wright.edu).

For further information about this research study, please contact Kimberly Sommers at (808) 349-7863 or at [sommers.13@wright.edu](mailto:sommers.13@wright.edu), or Dr. Julie Williams, faculty advisor, at [julie.williams@wright.edu](mailto:julie.williams@wright.edu).

## **Appendix E**

### **Demographics Form**

Thank you for your participation in this study. The information collected in this study is strictly confidential and will not be used in any way to identify you in any product of this study. Participation in this study is voluntary and you are free to decline to be in this study at any time. I appreciate your responses and all questions are optional.

1. Age:
2. Gender:
3. Ethnicity:
4. Relationship status:
5. Highest level of education completed:
6. Family composition:
7. Significant social support:
8. Military background:
9. Religion/Spirituality:
10. Occupation:
11. Current mental health diagnosis:
12. Previous mental health diagnoses:
13. Age when you were first diagnosed with a mental illness:
14. Other health concerns:

## Appendix F

### Interview Transcriptions

Names and identifying information has been changed to protect the confidentiality of the participants.

#### **Volunteer 1: Rebecca**

**Rebecca:** Do you want me to open in prayer?

**Interviewer:** If you want to, go ahead.

**Rebecca:** Dear Lord, please, please be with us. Bring us together perfectly. Be with us in this process of interviewing – to know exactly what to share and be with us and take care of us and forgive us of our sins and minister to us and be a blessing and in Jesus’ name, Amen.

**Interviewer:** Amen

**Rebecca:** This is fun!

**Interviewer:** I’m excited. Okay, so I’m going to start out by just kind of reading through what I have to read through.

**Rebecca:** Okay, okay.

**Interviewer:** So thank you for your participation in this study and for responding to the advertisement flyer that was mailed to the Schizophrenics Anonymous group. We are meeting at a public park to respect your privacy. Your responses are appreciated. The purpose of this interview is to gain a better understanding about what kind of questions clinicians should be asking people diagnosed with schizophrenia or schizoaffective disorder to address issues with treatment. Does that make sense?

**Rebecca:** No.

**Interviewer:** Okay, so basically what I am doing is I am interviewing you to get a sense of kind of your perspective on the treatment that you have received and what you would like what you would have preferred to get...

**Rebecca:** Oh.

**Interviewer:** ...out of treatment, you know, especially.

**Rebecca:** Okay.

**Interviewer:** Kind of when you were younger, that type of thing. So I’m exploring ... and this sentence is going to be kind of difficult too ... I am exploring the relationship between developing a personal understanding of the diagnosis of schizophrenia and schizoaffective disorder and how that impacts your willingness to participate in treatment. So that’s basically the idea of like, do you own, like how much does your willingness to say, “Yes, I do have schizophrenia” or anything impact your willingness to go into treatment, does that impact it? So while a great deal of research has been done and is being done on schizophrenia and schizoaffective disorder, the voices of people living with these diagnoses have not always been acknowledged and heard. I am here to ask you some questions about your experience of living with schizophrenia or schizoaffective disorder. Anything you tell me today will be kept confidential, in any way that it is used. Okay? This means that your name will not be connected to anything that you have said or provided to me. You do not have to answer any questions that you do

not want to, and you are allowed to end the interview at any time. There are eight questions and one questionnaire and this interview should take about an hour. There are no “right” or “wrong” answers and please be as honest as possible.

**Rebecca:** Okay.

**Interviewer:** Do you have any questions?

**Rebecca:** Well, like one thing that I deal with is, I needed medicine when I was a teenager.

**Interviewer:** Yeah.

**Rebecca:** But I didn’t get any that type of thing.

**Interviewer:** Oh, yeah.

**Rebecca:** Is that pertinent?

**Interviewer:** That is very pertinent.

**Rebecca:** And then when I was in first grade I wandered out of the playground in a daze.

**Interviewer:** You told me about that once.

**Rebecca:** And that wasn’t, that wasn’t my fault, it was my schizophrenia and the lady was mean to me and thought I was being bad.

**Interviewer:** So you feel that you had childhood schizophrenia?

**Rebecca:** Yeah, born with it.

**Interviewer:** Have you seen any of those media...? Oprah did a show about a child with schizophrenia.

**Rebecca:** Oh, I never heard about that.

**Interviewer:** It was interesting, really interesting.

**Rebecca:** Yeah, it was awful.

**Interviewer:** Yeah, it would be hard definitely. So we’ll get into that, but first, before we really get started, I need to have you sign this consent form.

**Rebecca:** Yeah.

**Interviewer:** So basically you can read through this, but what it says is – this is the title of my study. Real long.

**Rebecca:** Can you read that to me?

**Interviewer:** Disability identity formation in people with severe mental illness and treatment seeking and compliance: A participatory action research study.

**Rebecca:** Okay.

**Interviewer:** That’s the title of my study. It’s super long.

**Rebecca:** Okay, okay.

**Interviewer:** So basically this consent form is to say that you are willing to participate in this research study. This is who I am and where I’m coming from and why I’m doing this. So basically I’m Kimberly Sommers and I’m a doctoral student. It’s just talking about the purpose of my study. This is saying that your participation in this is completely voluntary and you can say that you don’t want to do it at anytime and you can stop the study. So I’m going to be asking you questions about your psychiatric disability and some other questions about age like I have a... it’s a demographics form that I’ll have you fill out asking a couple more specific questions, but all of this will not be connected to your name or your identity in any way so you’ll be assigned like a pseudonym or a number or something like that so in case this elicits any kind of psychological distress I gave you the number for CrisisCare in case that’s necessary, I hope it won’t be though. There won’t be any payment for participation, but I would very much appreciate it, and

hopefully it will lead to better understanding of schizophrenia and the experience of living with schizophrenia. Again, this says that anything about you will be kept strictly confidential and that your participation is voluntary and then further you can choose to not answer any questions for any reason that you want it doesn't matter you don't have to tell me what reason. If you have any question you can contact me at my email address or my faculty advisor Dr. Julie Williams at this phone number or at her email address and if you have questions about the study itself you can call the Wright State University IRB that's the Institutional Review Board, they're the ones who gave me approval to do this study. But to be strictly honest they don't know much about it and this just says that you have read and understood this consent form. So I wanted to walk you through it but you can take your time to read through it.

**Rebecca:** No, I think I'll just sign.

**Interviewer:** Okay, so go ahead and sign there and date. Thank you. Do you want a copy of this consent form? [Rebecca indicated that she did not want a copy.] Okay. So this next thing is a demographics form and I'm going to ask you to fill that out. You can move this closer to you so it's more comfortable to write on. So if you wouldn't mind taking some time to do that, and if you have any questions let me know.

**Rebecca:** What's this relationship status?

**Interviewer:** That means are you married, divorced, single?

**Rebecca:** Okay, single. What's this family composition thing?

**Interviewer:** That basically means kind of did you grow up with your mom and your dad? Did you have any brothers and sisters? Are you the oldest, the youngest, in the middle?

**Rebecca:** Mom, dad, younger brother. What's the significant social support thing?

**Interviewer:** Is there anyone that you consider really close friends that you call when you're struggling?

**Rebecca:** Yeah, I know who that is.

**Interviewer:** Okay. And how do you know them?

**Rebecca:** Church.

**Interviewer:** Okay. Would you mind just writing that?

**Rebecca:** Guess what she's going to do?

**Interviewer:** What?

**Rebecca:** She, Abby, Erin, and I are going to go to dinner.

**Interviewer:** Oh, nice. Do you know where you're going to go yet?

**Rebecca:** Not yet. What would other health concerns be?

**Interviewer:** If you have any kind of long-standing health concerns. I mean if you have a history of cancer or you know diabetes or whatever.

**Rebecca:** Okay, let's see.

**Interviewer:** Okay, great. I appreciate that. How was filling that out?

**Rebecca:** It was okay.

**Interviewer:** Okay, good.

**Rebecca:** You're so organized.

**Interviewer:** I have to be. Okay, so now we're going to move into our interview.

**Rebecca:** Do I just verbally do it and you write it down or?

**Interviewer:** I'm going to record it, but I'm also probably going to take notes, too, just to make sure for myself if I have any follow up questions, that type of thing. But mostly,



I'm going to record it so I can get it all. I'm not that fast of a writer. So my first question is when and how did you know that you had schizoaffective disorder or another mental illness?

**Rebecca:** Schizophrenia. Okay, this is the important thing. Okay. I was a teenager and the teacher in health taught about schizophrenia about catatonic schizophrenia and I thought I would be angry enough to just sit there and wait and not respond and have people like want to move me and I wouldn't react out of anger and I thought that's why I had schizophrenia. Then this girl stood up and talked about schizophrenia in her speech and I said that's me! I got schizophrenia.

**Interviewer:** So that was in high school?

**Rebecca:** Yeah.

**Interviewer:** How old were you in high school? What year were you in?

**Rebecca:** Freshmen.

**Interviewer:** You were a freshmen. Wow.

**Rebecca:** I was in junior high and then sophomore in high school was the speech and then also what happened was when I was in college I was feeling really guilty because I turned in my paper really late and my best friend had attempted suicide.

**Interviewer:** Oh, wow.

**Rebecca:** She really did commit suicide later.

**Interviewer:** Yeah, I think you've told me about her before.

**Rebecca:** Yeah and God helped me get over her suicide. But I couldn't think. And I cried out "Holy Spirit! Holy Spirit, teach me." And I got saved and before that I had gotten my first step to salvation going to the altar at A Religious College and saying, "Jesus, I know I cannot save myself, only you can save me." And then I had a break down and went in the hospital and got on psych meds.

**Interviewer:** And that was at Rebecca9? When you were first diagnosed?

**Rebecca:** Yeah, in the second quarter at A Religious College.

**Interviewer:** I didn't know, I knew you went to Local State University, but I didn't know but I didn't know you were at a different college.

**Rebecca:** yeah A Religious College and Local Community College and then Local State University and then back to Local Community College for one more class.

**Interviewer:** And then you finally completed the BA in French literature or French language?

**Rebecca:** Yeah, in French language.

**Interviewer:** Well, that's very cool.

**Rebecca:** I know. So that's how I knew I was sick – those three things.

**Interviewer:** And then looking back, I know you've talked about your childhood.

**Rebecca:** Yeah, what I needed was to go to the psychiatrist and get on medicine. What I did was go to this counselor that didn't do any good.

**Interviewer:** Oh, when was that?

**Rebecca:** That was after my breakdown.

**Interviewer:** Okay.

**Rebecca:** Right soon after my breakdown... wait... that was age 16.

**Interviewer:** Okay.

**Rebecca:** I'm sorry. At age ... man... at age 16, I saw this counselor that didn't do any good so we quit seeing them and I was so ashamed to be seeing a counselor and I should

have gone to see a different counselor or a psychiatrist because I needed to be on medicine when I was a teenager and I didn't get on medicine until I was 19.

**Interviewer:** Okay, and you went to go see this counselor and you said he didn't do any good? And that you were ashamed to go or...?

**Rebecca:** Yeah.

**Interviewer:** ...Or were you ashamed to go to him specifically? Or about going to see anybody?

**Rebecca:** Yeah, anybody. And I've been in and out of the hospital for 26 years.

**Interviewer:** Okay, and how many times have you been hospitalized?

**Rebecca:** Oh, about 13 times for about a year and six months.

**Interviewer:** Okay.

**Rebecca:** Something like that. Just in and out of the hospital. But there's been bright spots when I was well and doing great and not having any problems and stuff.

**Interviewer:** So it feels like it's kind have gone up and down sometimes.

**Rebecca:** Yeah.

**Interviewer:** Okay. So you knew, that's when you found out or when you kind of realized... how did you know for yourself that you had schizophrenia?

**Rebecca:** When I was in class.

**Interviewer:** When you were in the health class?

**Rebecca:** Health class, yeah, that's when I definitely knew. When I definitely knew.

**Interviewer:** Was it that you just recognized all the symptoms that they were describing?

**Rebecca:** Yeah, yeah.

**Interviewer:** Okay.

**Rebecca:** I guess it was God telling me and I didn't listen. You know like that and it was awful living with my parents because they would go into the bedroom and watch TV all evening and leave me, neglect me, and leave me on my own and I watched, sat down in the living room, and watched this tree grow and cried when snow hit the tree because I used to sit and watch the tree grow, but it was awful the way my parents were. When I was little they were like the best friends, and really nice and really interacting, and then they weren't anymore and mom said, "Well we didn't know what to do with you when you were a teenager." And it was just awful that they neglected me and stuff.

**Interviewer:** So you felt that they didn't understand you... or did you feel at all understood by anybody when you were a teenager?

**Rebecca:** No, no, no, no.

**Interviewer:** So your parents said they didn't know what to do with you. Did they say or notice that something wasn't going right with you or going well with you?

**Rebecca:** No, I was getting straight A's. So they thought I was fine.

**Interviewer:** Oh, okay. So you were still, so even though you felt that you had schizophrenia at the time and you were struggling with mental health concerns you were still getting straight A's.

**Rebecca:** Yeah.

**Interviewer:** That's impressive.

**Rebecca:** Thanks. But it was just just awful and I used to daydream my life away and it was just awful with my parents, and stuff like that.

**Interviewer:** So your parents were just watching TV... (Interruption from people in the park.) Do you want to take a pause since people are out here?

**Rebecca:** Whatever you think.

**Interviewer:** Want to keep going?

**Rebecca:** Whatever you think.

**Interviewer:** Okay, well let's move on to the next question. What do you think about your diagnosis?

**Rebecca:** It's true. It's very true. The schizoaffective disorder, bipolar type is the exact right, right one.

**Interviewer:** Has anyone sat down with you with that big gray book, the *DSM*, and talked about what it is specifically?

**Rebecca:** Well, no. But this girl, Sarah, the girl who came before you, do you know her?

**Interviewer:** Yeah.

**Rebecca:** Yeah she... I got lost. What were we talking about?

**Interviewer:** I asked about what you think about your diagnosis and you said it's true.

**Rebecca:** Well, she went through different diagnoses from the book and wrote down notes and talked about them one meeting like that. So that wasn't... She discussed bipolar and schizophrenia and stuff like that.

**Interviewer:** So was it then that you were like that diagnosis makes a lot of sense for me or is that your formal diagnosis at [Community Mental Health Center]?

**Rebecca:** Well what happened was that I went to [State Hospital]. Do you know [State Hospital]?

**Interviewer:** Yeah, in [City].

**Rebecca:** Yeah, in [City] and I went there and that's the diagnosis the doctor ... um... I don't know if it was before that or not, but for sure then. Dr. [X]. Have you heard of Dr. [X]?

**Interviewer:** I haven't, no.

**Rebecca:** Dr. [X]. He was a good Christian. He was into Christ and everything. Went to [A] Church and everything, and so he was the one, might have been the one to give me that diagnosis and he was the one that put me on Depakote and that's really helpful.

**Interviewer:** Okay.

**Rebecca:** And I want to tell you the Depakote story. He put me on a certain amount and then he moved it up and then he moved it back and then he moved it up and up again. And I kept saying 750! 750! 750! Because I thought that was the right amount for my body.

**Interviewer:** Yeah, you thought that that was the better dose.

**Rebecca:** Yeah, and finally because of the blood draw, he realized that I shouldn't be on higher and he realized I should be on 750, and he told my mom, "I hate it when the psychiatrist patient is right."

**Interviewer:** Awww. Well I'm kind of struck by that, because it feels like you sort of knew what you needed but...

**Rebecca:** And see I'm really mad at Dr. [Y], and my mom, and myself, because I promised I wouldn't go lower on the Lithium and I went lower on the Lithium and I think I shouldn't have gone lower on the Lithium and I see him on the 29<sup>th</sup>, 28<sup>th</sup> and I want to see if I can go up on the Lithium again.

**Interviewer:** Okay, yeah.

**Rebecca:** Because Dr. [Z] took me off the Lithium and I really needed it and here they are taking me off the Lithium again and I don't think I should be down on the Lithium I should be at the Lithium or with more Lithium.

**Interviewer:** Okay.

**Rebecca:** Because Lithium, you know, has helped.

**Interviewer:** Yeah, do you feel comfortable telling your doctors what it is that you need?

**Rebecca:** Yeah. I do.

**Interviewer:** Good.

**Rebecca:** Yeah, but Dr. [Y]. I get mad and hateful sometimes.

**Interviewer:** Oh, yeah, what's he doing?

**Rebecca:** Well, he wanted me to go off the Lithium and stuff, down on Lithium, but he did a wise thing and took me off the Lexapro. Ooh, that was great.

**Interviewer:** That made a big difference?

**Rebecca:** Yeah, because I'm not really struggling that much with OCD right now anyways so that was good.

**Interviewer:** Yeah, I saw that that was a former diagnosis for you, the OCD?

**Rebecca:** Yeah, way back when in '86 I had OCD, way back when I started with OCD.

**Interviewer:** Do you feel like you still have it or you feel like you've been recovered from it?

**Rebecca:** Recovering.

**Interviewer:** Okay. Recovering?

**Rebecca:** Yeah, recovering.

**Interviewer:** Okay. My next question is how did your friends and family react to your diagnosis?

**Rebecca:** Well, my dad and mom were absolutely besides themselves and petrified and upset when... See I was at college three hours away, so they came and visited me in the hospital, and they came and brought me home to the hospital up in [Suburb]. But they were besides themselves and upset and scared and having a tough time when they heard their daughter had a breakdown in college. Because I wouldn't call them, but my counselor called them.

**Interviewer:** So they had a tough time with it?

**Rebecca:** Yeah, my brother had the worst time...having trouble.

**Interviewer:** You all right?

**Rebecca:** Yup. (Sneezing.)

**Interviewer:** Bless you. Do you need a tissue or something?

**Rebecca:** Yes.

**Interviewer:** I can go run to the car real quick and get you a tissue, be right back.

**Rebecca:** Anyway, my brother. I'm just so mad at myself. Mad, mad, mad. I just don't believe what I did. I don't believe what I did. You won't believe what I did.

**Interviewer:** What did you do?

**Rebecca:** I went into the hospital when I shouldn't have.

**Interviewer:** Okay.

**Rebecca:** I got all depressed while I was in the hospital.

**Interviewer:** Were you depressed because you were in the hospital or were you depressed before then?

**Rebecca:** In the hospital. Because I was just on the upswing, I was going to be all right, and then I went into the hospital. I told my mom to call, to not go in the hospital, and she called to go into the hospital. I went to the hospital and I felt, I feel I told my brother a little about it, and I'm sure he's forgiven me because we're real close and everything, but the thing of it is the thing of it is, while I was in the hospital I was glad that my parents were ignoring my brother because they had to visit me all the time and he would always say, "Oh, do you have to visit Rebecca today?" and stuff. I feel very guilty about that and I told him that I was sorry that mom and dad visited me when they didn't pay attention to him and he wouldn't forgive me. But I think he's forgiven me by now because we are really close and stuff. So I feel really bad about my brother, so it must have been hard for my baby brother to have his big sister keep going in and out of the hospital all of the time for 26 years.

**Interviewer:** Do you know how he felt about all of that stuff you said that you're sure he had a hard time with it, but did he ever tell you about how he was feeling?

**Rebecca:** No. I just know that they told me that [Brother], my parents told me that my brother told them, "do you have to visit Rebecca again?" like that. So that was hard on my brother seeing his big sister in and out of the hospital for 26 years. He was nice though, he was nice. He came to visit me in the hospital two times. One year before and one year after because I was in [Suburb] psych around my birthday and I was in [State] Hospital psych next birthday and both birthdays he came to [Suburb] and to [State] Hospital to visit me on my birthday.

**Interviewer:** Oh, that's nice.

**Rebecca:** So that was really good and he he and so did you hear about the back-story?

**Interviewer:** I'm not sure.

**Rebecca:** Okay, so three years ago I thought I could fly three years ago I thought I could fly. This is really a true story.

**Interviewer:** So you thought you could fly?

**Rebecca:** Three years ago I thought I could fly. This is a true story. I was messing with the medicines and not taking them exactly as prescribed and my parents didn't know that I was doing that. So I jumped out of a two-story window and I fell and broke my back

**Interviewer:** I knew you had broken your back, yeah.

**Rebecca:** And so that was... What an ordeal that was!

**Interviewer:** I'm sure. I'm sure. That's a big time ordeal. So that was not taking your medications and messing around with that. Why were you doing that? Were you just feeling like you were better or?

**Rebecca:** I didn't have the wherewithal to keep at it exactly as I should. And mom and dad didn't know I was doing that.

**Interviewer:** Yeah. Were you living at home at the time?

**Rebecca:** No, this was at the lake.

**Interviewer:** So you were up in [State]?

**Rebecca:** Yeah.

**Interviewer:** So did you end up being hospitalized up in [State] or were you transported back home?

**Rebecca:** Yeah.

**Interviewer:** You were up there for a while I bet.

**Rebecca:** Yeah, up in psych ward up in [State].

**Interviewer:** Were you also in the medical unit at all?

**Rebecca:** Yeah, medical first, and then psych. Both. But every time I turned around they were doing a different group.

**Interviewer:** Yeah, I'm sure it was constant.

**Rebecca:** Yeah, I loved that.

**Interviewer:** How did your family react to your jumping out of the window?

**Rebecca:** They were not mad. They were not mad.

**Interviewer:** Were they scared?

**Rebecca:** They were not mad.

**Interviewer:** Yeah, I bet they were just worried.

**Rebecca:** Yeah, they and they came to visit me and stuff.

**Interviewer:** How did it feel to know that they weren't mad at you?

**Rebecca:** I don't know that I realized that they weren't mad at me at that time

**Interviewer:** Did you feel guilty at the time?

**Rebecca:** No, I think I did somewhat. The main thing was I got the help I needed at the psych ward. That was the main thing.

**Interviewer:** Yeah, that's good. So you got back on medications and kind of stabilized?

**Rebecca:** Yeah, and then we drove and had to have a 1.5-hour drive back just fresh out of the hospital. Ten hours home.

**Interviewer:** That's a long drive.

**Rebecca:** I just laid down in the back seat and we went.

**Interviewer:** That's a long drive. No fun.

**Rebecca:** Yeah, especially after just going into the hospital.

**Interviewer:** Yeah, so I think we've talked about this a little bit, but I just want to get a clear answer, how did you get involved in treatment?

**Rebecca:** Involved in treatment? Well, what happened was that I had the breakdown, went to the hospital, got on the medicine, went to the hospital at Kettering, went to see the doctor. Kept on seeing the doctor.

**Interviewer:** Was this the doctor at [CMHC]? Or have you been to other places?

**Rebecca:** This was Dr. [A] and Dr. [B] at [Private Psychiatric] so then let's see I had another breakdown and went away to [A Religious] College to [Large] Hospital in [City], have you heard of that hospital?

**Interviewer:** Yeah.

**Rebecca:** Okay. So then I went there and I was treated by Dr. [C] there and I should have stayed in the halfway house and gone to [Large State] University. I wanted to make an important point, aside, that is an important point that I wanted to discuss with you, can we come back to that later?

**Interviewer:** Of course.

**Rebecca:** Okay, my dad was an alcoholic when I was growing up. So I grew up with an alcoholic father.

**Interviewer:** Okay.

**Rebecca:** And my brother was an underage drinking so I deal with, had to deal with my brother with his underage drinking, and one time I had this horrific memory, but do you know [Joe] at [Suburb] psych, he leads groups and stuff?

**Interviewer:** No, I don't.

**Rebecca:** I cried on his arm and told him what had happened with my brother and God healed me, but have you heard of the term “dry drunk?”

**Interviewer:** Yes.

**Rebecca:** Okay, my dad’s a dry drunk.

**Interviewer:** Okay, so he hasn’t really changed his behavior, but he has stopped drinking?

**Rebecca:** Right.

**Interviewer:** Okay.

**Rebecca:** And it’s very, very hard. I don’t live with him, but I spend the weekends with him and the lake trip with him, but it’s very hard to have that happen.

**Interviewer:** Is that part of the reason that [Carl] usually asks for a prayer request for your dad to find salvation? Is that related to it?

**Rebecca:** Yeah. I don’t think he knows anything about that, but he still does that.

**Interviewer:** So he’s just putting it out there?

**Rebecca:** Yeah, I appreciate him doing that, but you know my dad is a dry drunk and it’s very difficult.

**Interviewer:** So the time that you spend with him can be less than fun?

**Rebecca:** Oh, it’s fun.

**Interviewer:** Yeah.

**Rebecca:** Yeah, we have a great time, mom and dad and I, but anyway I wanted to bring those two things to the forefront. Dad drinking. Brother drinking. Dad dry drunk and all of that.

**Interviewer:** Is [Brother] still struggling with alcohol?

**Rebecca:** What I do is pray every day for him to not drink one drop so it doesn’t interfere with work and his kids wouldn’t grow up with an alcoholic father. I pray that for him everyday. But I don’t know.

**Interviewer:** Yeah ok, that’s good for you to keep putting out those positive thoughts.

**Rebecca:** Yeah, yeah. So I wanted to bring that to the forefront.

**Interviewer:** I appreciate it, it gives me some more context so are we ready to go back to this question? So I asked you how you got involved in treatment and you said that you went to the hospital first and then got involved with a series of other doctors and a series of other places to stay.

**Rebecca:** Yeah, yeah, right.

**Interviewer:** Did you stay involved with treatment all the time or were there times when you were like “I’m not going to go to the doctor” or...?

**Rebecca:** Mostly went to the doctor. So I just kept on going to doctors and changing meds around and going to hospitals and all that. All that type of stuff.

**Interviewer:** So you never thought, “Oh, I’m better, I don’t need meds anymore”?

**Rebecca:** No, no. I mean I did, but I didn’t go off of it.

**Interviewer:** Okay.

**Rebecca:** I’m sure lots of times, I thought I didn’t need it but...

**Interviewer:** That’s pretty common that people feel like they don’t need this anymore that they’re better, that type of thing, that’s why I was wondering.

**Rebecca:** Yeah, because one time it was a danger.

**Interviewer:** What do you mean?

**Rebecca:** My friend [Sam], that I wrote down, I told her, I didn't trust anyone but her and I said, "[Sam], I want to go off my medicine."

**Interviewer:** And what did she say?

**Rebecca:** And she says "Rebecca, if you go off..." and I had already gone off of it for a little while, a few days, but it wasn't that toxic to go off of it for a few days so I was telling [Sam], the only one I trusted, "You know I'm thinking of going off the medicine" and she said, "Rebecca if you go off the medicine, you'll go right to [Suburb] psych." So I decided: okay, I'm not going to go off the medicine.

**Interviewer:** So that was a helpful response from your friend?

**Rebecca:** Yeah, and then I called her and said I'm staying on my medicine and she says that was adult and stuff, but like just yesterday I thought that the Lord was healing my mind and stuff and the way I felt in my mind I felt like the Lord was healing me and things like that but I'm sure I've gone off the meds a little bit, but like that.

**Interviewer:** Sometimes it's really hard to take medication as absolutely prescribed, you know what I mean?

**Rebecca:** Yeah.

**Interviewer:** So yeah, that makes sense that there were moments where you might have forgotten a dose for one night or taken it too late.

**Rebecca:** Yeah, right. My friend [Sam] says that I should take my medicine at the same time each day and stuff like that.

**Interviewer:** Ideally yeah. That's what you're supposed to do, but it is hard. Sometimes you want to sleep late?

**Rebecca:** Yeah.

**Interviewer:** Well, my next question: how do you define recovery?

**Rebecca:** How do I define recovery? Well, let's see. In my life, you wanted it from my life?

**Interviewer:** Yeah.

**Rebecca:** Okay, in my life, there have been many, many... I was thinking about this a month or two ago. In my life there have been many, many bright spots. Going on vacations, and things like that and managing my own medication. And going to the lake to Mackinaw Island and going to Arizona and going to lake ... with my dad and going to the Four Ladies and to Shenandoah. There have been so many bright spots.

**Interviewer:** Those are some nice trips.

**Rebecca:** Yeah, but I have sexual problems really bad.

**Interviewer:** Okay.

**Rebecca:** And I've been telling people that I sexually abuse their kids, but I haven't for a while and I just feel sexual feelings in my body against people and that's very hard on me and I think I almost sexually abused people or I did and something like that and it's really really hard and I fight against that. But this Letuta medicine is supposed to help and stuff.

**Interviewer:** Do you think it's helping?

**Rebecca:** Yeah.

**Interviewer:** Okay, good.

**Rebecca:** But my mom says, "You know if you cause any problems we're not going to the lake with you," and stuff like that.



**Interviewer:** And that's one of the bright spots that you identified so that has to be hard to have that threatened or that you have to work really hard to keep that as a bright spot, right?

**Rebecca:** And then, also, I feel like I have the gift of miracles and knowledge and mercy and I believe that I got a new cell phone, my mom got a new cell phone and gave me her old one, so I got a cell phone and I didn't have a cell phone but I thought that this girl was being... I looked at her and I thought she was being abused and I couldn't call because I didn't have a cell phone at that time and I couldn't call the police, but like if I ever saw this again, I might have to call the police and then they might have to take my phone privileges away, but it's more important to care for these kids than worry about my phone privileges and stuff like that.

**Interviewer:** Right, yeah. How do you think about the sexual problems and the idea that you think people are being abused or that you are abusing them? Do you... have you been told that that's a delusion?

**Rebecca:** Yeah.

**Interviewer:** Do you think it is? What do you think about it?

**Rebecca:** No, I think it's real. Last night I ran away from [Lance]. I kept running and running and running and thinking I was sexually abusing him and running and running and running away all the constant running away from [Lance]. And my friend [Brenda], do you know her from [CMHC]?

**Interviewer:** No, I'm sure if I saw her face, I might recognize her but I can't place her at this time.

**Rebecca:** Yeah she said, what was she saying?

**Interviewer:** I don't know. What was she saying?

**Rebecca:** I forget. I'm sorry

**Interviewer:** That's okay.

**Rebecca:** I forget what [Brenda] was saying. That's okay though.

**Interviewer:** So touching back on the question, you were saying that in your life, what recovery has been, is those bright spots where you felt healthy and well.

**Rebecca:** Yes, that's recovery for me.

**Interviewer:** Okay. What role does medication play in your recovery?

**Rebecca:** Medicines? Well, let's see. The Letuta is supposed to help with those sexual urges to tell and worry and not be able to sit with people. Now I cannot sit alone, be alone with [Lance] because Dr. [X] has made an edict.

**Interviewer:** Okay.

**Rebecca:** Because he does these sensual, he makes sensual noises and does sensual stuff and Dr. [X] says absolutely do not be alone with [Lance].

**Interviewer:** Is that why you were running away from him last night?

**Rebecca:** Yeah.

**Interviewer:** So medications, the Letuta is supposed to help but what other roles has medication played in your recovery?

**Rebecca:** Oh [Brenda] says she noticed that [Lance] is the one that I really run away from which is why I was thinking of it. Now what were you saying? I'm sorry.

**Interviewer:** What other roles have medications played in your recovery?

**Rebecca:** Okay, well the side... well, what I do is I have Clozaril.

**Interviewer:** So do you have to get blood draws all the time?

**Rebecca:** Once a month, but I'm really close to the blood draw people.

**Interviewer:** That's good. So I know earlier we talked about how you felt that you needed medications when you were a teenager but didn't get them. Did you feel like when you got medications that that made a big difference for you or not at all?

**Rebecca:** No, no, it didn't really help. I just took it because they said I had to, but it didn't really help I don't think. But what happens now is that it helps.

**Interviewer:** Okay, when was that change for you?

**Rebecca:** Well, I think it was happening at [State] Hospital when it really got straightened around.

**Interviewer:** With the Depakote?

**Rebecca:** I was straightened around, but kept having more and more trouble but then at [State] Hospital we did the Clozaril and that helped. I had thought all these weird ideas and it flushed out all those weird ideas and then the Clozaril helps my mind so I have to take the Clozaril for my schizophrenia. Then for my Bipolar Type I, I have to take Depakote and Lithium and I don't know if there are any other ones for that.

**Interviewer:** And then there's the Letuta for the sexual problems?

**Rebecca:** Yeah.

**Interviewer:** Okay. So when were you at [State] Hospital?

**Rebecca:** I was at [State] Hospital over two months between, not this Christmas, but the Christmas before.

**Interviewer:** Okay. So Christmas?

**Rebecca:** Yeah. Well, I was entered on the 8<sup>th</sup>, 8<sup>th</sup> of December and got home on the 14<sup>th</sup> of February. I was over two months at State Hospital and I was on Depakote, Lithium, and Clozaril for my psych needs and ...

**Interviewer:** And that was the first time those medications were helpful?

**Rebecca:** Yeah. Well, the Clozaril. Well, my mom told me that Clozaril was the only thing that ever worked and I was put on that in 1994. And the Clozaril stopped working and mother said that we should have kept the Clozaril and just added instead of taking away the Clozaril. I'm not sure that she's right about that.

**Interviewer:** I know sometimes the efficacy of medications can wear off and when you get it out of your system and reintroduce it, it can work again.

**Rebecca:** Yeah, and mother said that if you would ever have to go off Clozaril it would be a disaster because it's the only thing that ever worked. And one time my mother and [Steve] and me and [Steve's] mom, we all went to a conference in [City] talking about the importance of Clozaril in our lives.

**Interviewer:** It's a pretty effective medication.

**Rebecca:** And see I was like so manic at [State] Hospital that's why he had to put me on Depakote because I was so manic.

**Interviewer:** What has had the greatest impact in your recovery?

**Rebecca:** [Sam].

**Interviewer:** So your social support, yeah?

**Rebecca:** [Sam, Abby, Erin, and Flo]. Friends from church.

**Interviewer:** Why have they had the greatest impact for your recovery?

**Rebecca:** Well, [Sam] listens to my problems and tries to help and...

**Interviewer:** Makes a difference to have that support?

**Rebecca:** Yeah, she she's going to call and we are going to go out to dinner with a couple of our friends.

**Interviewer:** That's nice.

**Rebecca:** She listens to me and hugs me and prays for me and all of that and then [Abby] is going to join us for lunch too and [Erin] is, she's [Sam's] friend, and I know her from singles' group and she's going to join us for lunch, too. And [Sam] is heading off to New York to be with her family tomorrow, but when she gets back.

**Interviewer:** Then you'll go out to dinner?

**Rebecca:** Yeah, and then we'll go out to dinner. So it's really helpful to have good friends. Good, Christian friends.

**Interviewer:** People that can listen and help you and support you.

**Rebecca:** Yeah, that's important.

**Interviewer:** My last question and this I'm not sure... What would be important to know about living with schizophrenia?

**Rebecca:** Every little thing can set you off. Getting mad, getting hateful, getting scared, running away, fear of dad, fear of mom, dealing with dad with his dry drunk. What was the question again?

**Interviewer:** What would be most important for people without schizophrenia to know about living with schizophrenia?

**Rebecca:** And then dealing with my dad, taking the medicine, knowing who to trust when, because my mom will say, "No, you didn't do anything wrong. Let's go." And she'll grab me and say, "You didn't do anything wrong, let's go." And so what I need to do, they need to understand what I need. I need to get my naps in. I need to get my chores in. I need to get my walk in.

**Interviewer:** So there's a need for structure to keep you safe and healthy and in recovery?

**Rebecca:** Yeah. Need to tidy up more better and sometimes you just need to take time for yourself. You cannot worry about anybody else, you just have to take care of yourself or you're going to have a breakdown.

**Interviewer:** So it's a lot of work to keep yourself well?

**Rebecca:** Yeah. My dad says that I have triumphed over mental illness and his friend [Linda] who is struggling with cancer, dad and I saw her at the grocery store, he says, "Oh, we're so proud of her" and stuff.

**Interviewer:** That's good.

**Rebecca:** Yeah, I don't know that there's anything else they need to know. How hard it is to trust the doctor.

**Interviewer:** Yeah. I think that's really important for people to know because I think some times people who don't know anyone else with schizophrenia may ask, "Why aren't they just on meds and just fine and blah blah blah..." But it is really, really hard to figure out what's going to work best for you, what's going to help you succeed and be functioning better than you were, that type of thing and how hard it is. And as you describe things, how much of your day is taken up by making sure that you're okay.

**Rebecca:** Yeah, I love doing laundry.

**Interviewer:** Well that is the last of my questions. Is there anything we didn't touch on today that you want to make sure we talk about?

**Rebecca:** Well, the importance of hugs and kisses and loving Jesus and stuff like that.

**Interviewer:** The importance of feeling supported and loved. That social support, again, is really important. Okay, well, I really appreciated your time Rebecca.

**Rebecca:** Yes, this is lovely.

**Interviewer:** And I'm excited. I'm glad that you suggested this park and that we had a good conversation. I really, really appreciate it.

**Rebecca:** Yeah, I've been praying for you and I'll keep praying for you.

**Interviewer:** So what are we doing this evening at S.A.?

**Rebecca:** Let's see. We will be talking about steps seven: I choose to live and Step two. I'm really having difficulty, and I'm afraid I'm going to have a breakdown and struggling with thoughts. But I think if I can get my laundry started and go to S.A. that will help my mind and I have to think about how it's not really there.

**Interviewer:** So even in this moment you are feeling a little bit frightened?

**Rebecca:** Overwhelmed.

**Interviewer:** Okay. Is there anything I can do to help?

**Rebecca:** Well, don't forget to pray for me.

**Interviewer:** All right. Okay. I hope laundry and coming to S.A. will help you feel less overwhelmed today.

**Rebecca:** Well, mom and dad are going to lake soon and she has to get over her cold and get ready to go on vacation.

**Interviewer:** Well, I hope they have a nice time. Is there anything else you would like to share?

**Rebecca:** No.

(End of interview)

## **Volunteer 2: Frank**

**Frank:** Let's see. The first time I noticed I had some problems was in the winter of 1973.

**Interviewer:** I want to get back to that because that's very much the first question, but I want to make sure that we have this paperwork stuff that we have to get done in time so I got to read this to you and have you sign a consent form and do something else and then get started because my first question will be "when and how did you know?" and so I'm glad you're right there with me.

**Frank:** Okay.

**Interviewer:** All right, so I'm just going to read this, it's going to sound weird. Thank you for your participation in this study and for responding to the advertisement flyer. We are meeting at a public library to respect your privacy. Your responses are appreciated. The purpose of this interview is to gain a better understanding about what kind of questions clinicians should be asking people diagnosed with schizophrenia or schizoaffective disorder to address issues with treatment. You know, getting to understand your experience? I am exploring the relationship between developing a personal understanding of the diagnosis of schizophrenia and schizoaffective disorder and how that impacts your willingness to participate in treatment. Any questions about that?

**Frank:** No.

**Interviewer:** Okay, while a great deal of research has been done and is being done on schizophrenia and schizoaffective disorder, the voices of people living with these diagnoses have not always been acknowledged and heard. I am here to ask you some

questions about your experience of living with schizophrenia or schizoaffective disorder. Anything you tell me today will be kept confidential, in any way that it is used. This means that your name will not be connected to anything that you have said or provided to me. You do not have to answer any questions that you do not want to, and you are allowed to end the interview at any time. There are eight questions and one questionnaire and this interview should take about an hour. There are no “right” or “wrong” answers and please be as honest as possible. Do you have any questions?

**Frank:** No questions.

**Interviewer:** All right, so this next thing is a consent form, just kind of running through it pretty quickly. This just says that you are consenting to do this study with me. This is where I’m coming from and what I’m studying. This just says that your participation will involve the 1-hour interview that type of thing and that the tape and the information, I’ll hold it until I’m done with the study, and then it will be destroyed.

**Frank:** Okay.

**Interviewer:** What else? Basically, confidentiality again.

**Frank:** There will be no direct benefit to me from participating in this study?

**Interviewer:** Right, yeah, I’m not giving you cash.

**Frank:** Darn.

**Interviewer:** I know, right? Again, participation is totally voluntary, if you decide you don’t want to go on anymore, that’s fine. I’ve provided CrisisCare’s number in case you are distressed, but I hope you wouldn’t be. I think that’s it for this page. Over here there’s contact information for IRB so if you have any questions you can contact them or my faculty advisor, Dr. Julie Williams, and that’s basically it. And I can give you a copy of this, the consent form, if you want.

**Frank:** Sure, sure.

**Interviewer:** Okay, so this will be the only thing that has your name on it.

**Frank:** This is the [x]<sup>th</sup> right?

**Interviewer:** Yeah.

**Frank:** I don’t keep my days straight.

**Interviewer:** Me either. So that’s your copy for you to take and I have to sign, too. Okay. The next thing I’m going to have you do is this demographics form and this just kind of gets that straightforward information from you.

**Frank:** That’s what they call that, the population... strata.... something like that.

**Interviewer:** Yeah, but it’s basically for my study to make sure I got, you know, since I’m going take your name off of things, it’s just to get general information and some background info.

**Frank:** I can’t write very well after a while because of the effects of the medicine.

**Interviewer:** Okay, if you need any help writing things let me know and I can transcribe for you.

**Frank:** Trying to think about other health concerns. I think I spelled that wrong. Let’s see.

**Interviewer:** Is that supposed to be high cholesterol?

**Frank:** Yeah.

**Interviewer:** Cool, I can read all of it. Okay, so where we’ll start is basically that I have these eight questions and they’re kind of about trying to hear your story, so we’ll see what we come up with.

**Frank:** Sure, sure.

**Interviewer:** Okay, you sort of started answering the first one when we first sat down. So when and how did you first know that you had schizophrenia or schizoaffective disorder?

**Frank:** Well, let's see. The first time I had problems I think I was in, when I was in the Air Force, around December of 1972, I believe, and what it is, my roommate seemed to notice bizarre behaviors. He didn't say much. All I know is, I was hearing things that were not really going on.

**Interviewer:** How did you know that they weren't really going on? Or did you think they were?

**Frank:** Well, my roommate, my bunk buddy, was in the room with me when I allegedly heard these things and I said, "Did you hear what's going on? Do you want to call the police?" And he said, "What police? For what? I don't hear anything." And that's when I kind of noticed that I had a problem.

**Interviewer:** Yeah.

**Frank:** About two months, well not two months, about a month after, I was in tech school and we were on break and I came back and we had gone out to one of the restaurants off base and came back and I started to get very nervous and there was no kind of, any kind of indication that I had to, taken any drugs or eaten anything that would make me sick. But I started to get extremely agitated and I do remember clearly that I ended up screaming at the top of my lungs. The environment I was in, even though the buildings were pale colored; they seemed to be vibrant, very deep color. They whites were very bright and the building colors were very technicolored. So that went on, that went on, for I don't know, for about 10-15 minutes and they took me to the head NCO for the shift and they asked me a few questions and he said, "Well, we have the ambulance coming, so we'll take you there." And I was on the hospital ward at the air force base and I was there for three weeks but there was no diagnosis at that time given.

**Interviewer:** Yeah, do you know if they diagnosed you with something and just didn't tell you about it or do you know if there just wasn't one?

**Frank:** They probably did. They probably didn't tell me. They probably did have a diagnosis, but didn't tell me. And I think, too, that my commanding officer in the squadron that I was in wanted me to complete training so they wanted to withhold that diagnosis because it might change.

**Interviewer:** Right, yeah.

**Frank:** So I did complete training and the next duty station I was in was in [X] Air Force Base in [State] outside of [City] and I started to hear voices and I said, "This isn't right." First of all, what I would do is check it out. I had the courage to get out of my room, get out of wherever I was, and go to the source of where I thought the voices were coming from. At first, I thought, "Oh well. Heck, maybe someone's in the building throwing their voice." You know, playing a joke on me, that kind of thing. So you know, anyway, that wasn't what was really going on with me, it was just...

**Interviewer:** Yeah, you were hearing things.

**Frank:** Yeah.

**Interviewer:** Did you ever check with somebody else, too? Because I know when that first happened you were with your roommate. But did you check with other people, too?

**Frank:** I didn't at this time. I didn't. But another thing that happened, which was really, really sent me, you know, going to the clinic. I was watching this program, by what was it called? "To tell the truth." I think it was called "To Tell the Truth." And this was like a long time ago. But Gary Moore, I don't know if you remember him, he was an entertainer. He's been dead now for about 20 years. He looked in the camera and he looked at, well, it seemed like I was watching him on TV and he looked directly at me, and he said, "You got to relax."

**Interviewer:** Oh, okay.

**Frank:** And I said, "Uh oh, this is not right." So some of the other... Well, there was a couple of other people with me watching the TV program and they didn't see it. So I said, "Well, why did that guy say it?" And he said, "Well, he didn't say anything. He just said 'Welcome to the game show.' That's all he said." And I said, "That's not what he said." So I didn't want to argue so they said, "Just get some rest." So I tried to sleep, but didn't get very much rest.

**Interviewer:** Yeah.

**Frank:** And I reported to work and I was pretty agitated. I was starting to sweat and my eyeballs were getting reddish and were just darting around looking at stuff and so the sergeant told me, "You better just go to the clinic." Took me to the clinic. Meanwhile, I started shivering. Ended up at another hospital about 40, 50 miles away. And they didn't strap me down, nothing like that, but they gave me this blue pill and I asked them what it was. And he said it was Stellazine and I said, "Never heard of it" and he says, "Just take it. Just take it." And I was like, "There's nothing wrong with me. I'm fine. I'm fine. I just need some rest." And the nurse said, "No, no you better take this." So I took it and I don't know how long I slept, I really couldn't tell you, but I did feel better the next day.

**Interviewer:** Yeah, yeah, and were you feeling better like you just got some rest or were you feeling better like your head was feeling a little bit clearer?

**Frank:** My head. I felt like my head was getting clearer.

**Interviewer:** Okay, okay.

**Frank:** And the rest did help too. So I thought, "Well okay, that's cool." So I told the nurse that I would like to see the doctor and, you know, report back to duty and she said, the nurse said, "Well, you got to wait and we'll give you some more medicine to see what else happens." So I continued to take the medication and I think the third day or the fourth day after taking it I was constipated. And that wasn't, that wasn't the greatest.

**Interviewer:** That's not pleasant.

**Frank:** Yeah not pleasant at all, but anyway. So I continued to take the medication and for a while there I could only eat there in the hospital ward and then after about a week they were allowing me to go over to the mess hall and eat meals there and, of course, I had to be supervised. They had to watch me because of my [ineligible] so after I think I was there for about two months.

**Interviewer:** Oh, wow.

**Frank:** And then they sent me to another hospital at [Y] Air Force Base because they thought they felt that the facilities at [Z] Air Force Base was not good.

**Interviewer:** Yeah.

**Frank:** So to make a long story short, I was there for about three months at the end of the second month my grandmother, my mother's mother, passed away so they gave me a

bereavement leave and I was there for... I was in Indiana for about 20 days and I seemed to respond fairly well.

**Interviewer:** Doing okay outside of the hospital environment?

**Frank:** And I wasn't taking the medication at full dose, just enough to keep me calm so, you know, I knew I had to report back, so I flew back to [Y] AFB and uh well...

**Interviewer:** So you were on leave from both the Air Force and the hospital for those 20 days?

**Frank:** So they flew me from the AFB over there and back and I didn't have to pay a cent, which was nice. It's nice, so you know, anyway.

**Interviewer:** So you went back to [Y] AFB?

**Frank:** Right, to the AFB's hospital and I was there for another month and they said, "Well, pack your clothes, Frank. We're sending you home."

**Interviewer:** Okay.

**Frank:** Well, a couple of days before that they asked me – not asked me – told me that I have to take a disability arrangement from the [ineligible] and I said, "Well, I don't want that because I want to stay in the Air Force, I want to work."

**Interviewer:** Yeah.

**Frank:** And they said, "No, you can't. Sign this paper." So I signed the paper and the next thing I know it's two or three days later and they told me, "Well get your duffel bag and go." So I was flown back and I was staying in the VA hospital in [City] and for 30 days and I was messed up. I'm telling you. I couldn't talk, I couldn't walk, I couldn't do anything. I was seeing things I had never seen before. Guys walking on the ceiling and I was like, "Whoa, what's going on with that, this is totally weird." No, no, no.

**Interviewer:** That's interesting. That kind of, before you ended up in [City] you were doing sounds like...

**Frank:** I was doing well.

**Interviewer:** Yeah. Right. But it sounds like that change in environment really, really...

**Frank:** Shook me up.

**Interviewer:** It threw you through a loop.

**Frank:** Well, the hospitalization that's what, that's what got me the most because I, they told me I had a problem. They told me that I couldn't be out in public. So like essentially it was like being in jail.

**Interviewer:** Yeah.

**Frank:** So you know I was thinking, "Well I must be really, really sick because they are keeping me in the VA." So you know my mother came by to visit she didn't seem to see me as the same. My brother was angry because, you know, here I was, you know, pretty good guy, making good grades in school, able to socialize as well, and kind of respected by my peers and stuff, and he was beside himself, and he said, "If you guys ever hurt my brother, we'll sue you for every last single dime." So they kind of backed off on wanting to give me electroshock therapy. Oh, ECT, no the other one, ECT.

**Interviewer:** Yeah, electroconvulsive therapy.

**Frank:** Yeah and um...

**Interviewer:** Did they give you a reason for that?

**Frank:** Well they said that, they said that the way my brain operates, there are two ways of operation. Mainly it's chemical, but it's also, too, electrical because of the nerves and neurons interacting with electricity, so the ECT would be disrupting...



**Interviewer:** Yeah, the electrical activity.

**Frank:** Right. So the brain could reboot in so many words.

**Interviewer:** Like a computer.

**Frank:** So I thought, “Well, it’s worth a chance.” But my mother said, “No way. No way.” So they talked to the doctor and they said, “Okay, we’ll try some different medications.” After about a year of taking the Stellazine they changed me over to Thorazine and it was okay, but I was zoned out. I couldn’t do anything. I was gaining weight. I still have the results of that.

**Interviewer:** The side effects just weren’t worth what you were getting out of it?

**Frank:** Right. It was really more painful. My back was stiff so they stopped doing that. They put me back on Stellazine on a lower, well somewhat lower, dose. They gave me Cogentin to fight the side effects. Anyway, make a long story short; my relationships with my friends had changed because they saw a difference in me. I couldn’t date any girl. Just things just didn’t work out. I just didn’t seem to act okay around them.

**Interviewer:** Really impacted your whole life?

**Frank:** Yeah. I ended up being a loner. But first thing I had some income so I saved up some money and got a nice apartment and I lived there off and on for, I don’t know, four or five years and did fairly well. I didn’t work at any particular business I did different jobs and most of them were part-time low-paying jobs but I didn’t care, I just wanted to do something.

**Interviewer:** Yeah.

**Frank:** You know, so one day I got a letter from the VA and they said, “Well, we can pay for your education.” And I said, “How do I? What do I have to do?” And they said, “Well, you have to qualify. You have to be some many percentage disabled and you had to serve at least a year in service.”

**Interviewer:** How long were you in the service?

**Frank:** Only a year and three months. At that time, at that time, they’ve changed it because it used to be a year, and if you served a year in the military, you would eligible for all of the benefits that the VA could give you, but now they say you have to serve at least four or five years to get qualified, unless you were disabled – if you lose a leg or you’re mentally ill. So anyway, the first diagnosis after I was at the VA that I got was paranoid schizophrenia. I don’t know whether it was undifferentiated or differentiated, which means it’s like a quasi kind of thing, diagnosis, because they were really sure if it was full-blown schizophrenia or if it ...

**Interviewer:** Or if it was something else?

**Frank:** Yeah, or something else. So they put that in the diagnosis and when my mom found out, no one in our family ever had a mental disorder.

**Interviewer:** How did your friends and family react when they found out?

**Frank:** They said to me, they said, that they loved me and they would do anything for me to make me better. They supported me. They didn’t ostracize me from the family. But I was at a point in my life, I thought if I’m behaving this way, then I cannot be a member of the family.

**Interviewer:** So you were trying to take yourself out?

**Frank:** Yes. I did not want to live up to the name of my family because I wasn’t. It just didn’t seem like I was able to because of this diagnosis and the way my behavior was. So anyway.

**Interviewer:** Did you spend a lot of time avoiding your family around that?

**Frank:** Yeah, I did occasionally. My mom would come by to see me and she would bring me groceries and, you know, help out. And my brother, he tried to get me involved in sports again and I just couldn't. Of course, I did cheer my brother on when he was playing pro sports. You know I felt pretty good about that. But I just knew that my enjoyment of things had changed. I couldn't watch TV because of the voices.

**Interviewer:** I know you've talked about, since then, recently, you've had some of those moments where you felt that the person on television was talking to you directly, and kind of being freaked out by that.

**Frank:** Yeah, yeah, well, also, too, the other thing is that my stepmother passed away and then my dad passed away. Before that, my mom had a stroke in early 2002, I think 2001. My ex-wife was diagnosed with kidney failure and all kind of other stuff and my son was not doing well.

**Interviewer:** That's a lot of stress.

**Frank:** Yeah, it's a lot of stress. It is a lot of stress. But the, what the meds do, to me, is it numbs me up so I don't feel as distressed as others because if I did, I probably wouldn't be alive. I would have just gone out and do that (*makes a pfft sound and gestures cutting his wrists*). As a matter of fact, I did try to do that, but it wasn't until after I was married, after my wife left. For a long period of time, I was in and out of the VA medical hospital quite often. In [City] and also here in [State], and see, I can remember all of this because it's very vivid. I have, there's another diagnosis I didn't put on there, it is PTSD.

Because it causes me to react present-day problems as it relates to what happened to me earlier.

**Interviewer:** Yeah, yeah.

**Frank:** And that's how I've come, as a way to deal with it. You know there's a lot of veterans both Vietnam era and Iraqi era that have it and I think it's because of the way we were trained. We were trained differently from the way they were in WWII. Because I think in WWII there was something, we were jumped upon by other countries and attacked by other countries whereas in Vietnam and Iraq we were the ones that initiated the invasions and I think there is a question of moral behavior in that. So since Vietnam, a lot of veterans, so you know, the war was not fought right, it wasn't supported well, and all of that, so there is a difference.

**Interviewer:** So you think there is a difference then in trying to, kind of, feel justified in some of these really harsh acts, that type of thing?

**Frank:** Yeah. So...

**Interviewer:** Is the PTSD diagnosis still current or is that no longer on file?

**Frank:** I'm not sure. I'm not sure. I have a new psychiatrist, so she's working on her diagnosis.

**Interviewer:** Do you agree with your... what do you think about your diagnosis? Do you agree with it? With the schizoaffective, bipolar type?

**Frank:** Well, the, you know to me, it seemed to be a relief. At least they knew that something was going on. Not that I want to use it as an excuse, you know, I don't. I just want to be regarded as normal as anybody else. And in some cases, schizophrenia can be a normal-acting behavior person so there, really the only real way you can tell a person is schizophrenic is by the stress that they handle and by the response that they have.

**Interviewer:** So stress is a big trigger for you?

**Frank:** Yeah, very big. Yeah, I was going to school in the service. We had to go in six hours shifts and we would be on one hour before and one hour after, so we are talking about eight hours and in my situation, well in a lot of our situations, they just required us to go to tech school. It was too much time for our shift and for like a month we would be on C shift, which would be from six until midnight and the next month we would be on B shift, which was like 12 noon to six pm and then shifted over to A shift, and you know so, six am to 12 noon. So anyway, all that different shifting does create some stress. Most military individuals can handle that kind of change. I couldn't.

**Interviewer:** Do you know anything about Bipolar Disorder and how it relates to that sort of needing to shift your time?

**Frank:** Yeah, the obsessive part of kind of makes you think more about the time you are spending. And the stuff that you are studying, you need to be able to concentrate and remember what you are reading and examining. And the depressive. Yeah that's because, due to our need for rest and, also, too, when we cannot address certain problems and we generate or what someone else generates then we get angry and instead of directing that anger at somebody else, we couldn't cause of the way...

**Interviewer:** You'd turn it inward?

**Frank:** Yeah, turn it inward because that's the way depression starts, in some cases.

**Interviewer:** I also know that not having a set schedule, can set off, you know, kind of a manic or a depressive episode and creates stress too?

**Frank:** Yeah, I'm sorry, I didn't mean to obsess.

**Interviewer:** No, no, it's okay

**Frank:** Well, I tried to go to school. I tried to go to college at least three or four times, at least, and no success. The last time I went to school here at [Community College], I was sitting in class and my brain just locked up and I just couldn't get my head around what they were talking about, so I just picked up my notebook, textbook, and got my coat on, and I just walked right on out of the school and they haven't said anything to me and this has been what two or three years and that was all. My brother was mad at me because he said, "You're a quitter." And I keep telling him, "I'm not a quitter I just don't have that same ability I had when I was younger." And so, but I think if I continue taking the medications right, and if I get enough rest, and I have the right diet, I will probably be able to complete a degree I hope.

**Interviewer:** What do you want to complete a degree in?

**Frank:** Well, I don't know. I'm thinking of computer science. That might be a hard field of study, but I have some experience with computers so I think I could do that. Well now, as far as success is concerned, as far as getting a job with that, I'm 61, I don't care.

**Interviewer:** Is it more about attaining the degree and getting an education?

**Frank:** Exactly. Instead of going to get a career job, it would nice if I could, you know, just to keep busy, but I probably won't have the ability to do that. But anyway, my step grandfather, on my father's side, was a high up officer for the University of Chicago, Chicago Circle campus. My grandfather, my father's father, was the first president of a grad chapter of a fraternity, Phi Alpha fraternity. My dad spent quite a few years as a general ambassador, not ambassador, delegate, to the different conventions of that fraternity. My aunt, his sister, had a Ph.D. in education, she has a masters in education and she was a teacher for a while. My grandmother, my father's mother, was a social

worker and then when she met my step grandfather, my step grandfather was a circuit court judge in Chicago, Illinois. So I haven't a lot of things to look up to.

**Interviewer:** Yeah, you have a long history of success in the family.

**Frank:** Right. And people will say, "Oh you're just trying to over-achieve." And I say, "No, this is just the way we are, this is what is expected." Now my younger brother is a claims adjuster for an insurance company, he does freelance contracting. My other brother, he works as a CIO, which is a chief information officer for the County Health Department. My youngest brother works for an alderman in Chicago, taking care of businesses related to the government. So we're all, have some form of ability so I felt so ashamed because of the history.

**Interviewer:** So is that part of the reason, going back to that question, about how your family reacted to your diagnosis, and they were supportive...

**Frank:** Yeah they were supportive, I wasn't.

**Interviewer:** You were kicking yourself out of the family?

**Frank:** Yeah, because I felt, you know, I could've gotten away with that kind of behavior, I should have figured out a way to act normal and you know I can't. That's the thing that gets me.

**Interviewer:** Well, I have to ask you a question about that, kind of that want to get back to normal, so I'm wondering then, how do you define recovery?

**Frank:** Recovery for me would be that, instead of getting overly panicked, overly nervous, that that nervousness would only last for, at the most, five to ten minutes, at the most. Normal for me would be to be able to enjoy TV programs that I really like to watch. Being able to walk outside, down the street, without thinking that someone is talking about me. Also, too, thinking about the people on TV aren't thinking about me. They are mainly just doing their thing, they are actors acting, doing whatever they're doing. You know, I've had a lot of thought. I was thinking, you know, this isn't really the real world, and this isn't, kind of, a large reservation where they keep all the mentally ill people in an arena and they've got a large, large, large array of defensive weapons out there that will vaporize anybody that tries to get through the barrier. You know it's really weird that I think like that but I'm just saying that I flew back from New York, no Washington DC. I didn't travel by bus, so I didn't really know where the heck I'm at.

**Interviewer:** I think the theme that I'm hearing a lot from you about what recovery means is to not be afraid.

**Frank:** Yeah, right.

**Interviewer:** Anymore? Or to be afraid, when it's appropriate and everyone else is afraid, too?

**Frank:** Yeah, being able to be appropriate. That's another thing, too. I laugh sometimes at other people's misfortune.

**Interviewer:** Well, a lot people do that.

**Frank:** Well, some people somewhat, but you know, if it's a, they feel, they take it like I'm making fun of them. And with me, it's automatic. I just don't, I don't have the idea that I'm trying to be over them. I'm just laughing because I think it's funny and it really hurts. I feel like I once laughed at my grandmother's funeral.

**Interviewer:** So there's moments where you have "inappropriate affect" you end up feeling really bad about it for a while then?

**Frank:** Yeah well now too, trying to convince my family that I'm somewhat patched back together. With them, it's okay. They take me in that regard, but whenever I feel together, and I go out there in public, it's always something that comes up that makes me go right back into that kind of behavior of what I am and I'm back at square one. And it doesn't have to be a remembrance of things I have done in the past, it just has to be something that would affect the way I behave. I react to what someone else is saying or doing, so you know, that's the part that I really don't like and I wish that if I were normal that that wouldn't be a major problem that I would just go on about my business and stay happy.

**Interviewer:** For me that goes back a little bit to that idea of living without fear and also keeping the progress that you've made, too.

**Frank:** Yeah there's big stakes in that.

**Interviewer:** What role do medications play in your recovery?

**Frank:** If it hadn't been for medications, I wouldn't be sitting here talking to you. I would probably be dead either by getting into a fight with somebody and they beating me to death or getting shot at or killed or me just taking a flying leap off a building and that would be it. Because I've had so many things I've failed at that, you know, marriage, raising the children, being able to support my mother and father because they had retired after I got married, you know, staying in the marriage being able to be an influence on my children so that they would be successful that they'd be able to cope with the various stressors in society, you know, having a degree that wasn't on the top of the list, but it's up there, it's up there. The more education, I thought that the more education I would have, the better able I would be to cope with society.

**Interviewer:** Back to the medication piece: has there ever been a time when you thought, "I don't need this medication I'm going off of it"?

**Frank:** Yeah, I've gone off of it at least five times over the past 25 years and each time, you know, after a day being off the medication I just go bananas. I'm just totally out of it, and you know, my brothers they know, they say, "You cannot be around me or the kids without the medications." So my brother does work at the intake department for people who have mental disorders. So he sees first hand the most violent persons that come into that care, and he says that some of the other repeat offenders that come in are given the harshest treatment by the police or by the...

**Interviewer:** Mental health professionals there?

**Frank:** Yeah the mental health professionals, because when they start to get incoherent or they start to act up or act out as they say well then they put them away in seclusion and the only way to guarantee that they'd still be alive is to place them in an area where there's one or two of these officers would be able to see and hear what they're doing. So they have to have these cages with glass this thick and there's only one door that's about halfway down that you can see invisibly into the cell and ...

**Interviewer:** The cell's no bigger than this room?

**Frank:** Exactly. And my brother said you don't want to be there. His daughter has mental illness and so we are trying to deal with that. My brother's wife, who is the daughter's mother, had a mental illness herself. She developed it after giving birth to the youngest daughter and the thing that made it stressful for her was she had these children in a five or six year span. Four girls.

**Interviewer:** Oh my word.

**Frank:** So there wasn't any continuity of care for her. She didn't have time to give to her relationship with my brother. She didn't have time to really bond with these children because she ...

**Interviewer:** Was pregnant right away?

**Frank:** Right, three of them were a year and some odd months apart. I don't want to criticize him about it. But I'm saying, "My God, don't you give a person some rest?" Now with me and my wife, well our first child was born about a year and a half after we were married and then the second child wasn't born until almost two years later and that's what I want, that's what I wanted our family to be like, so I don't blame her for being how she is. She's not there now; she's at... well I shouldn't say too much about that, I'm supposed to be on my brother's side about all of that so anyway.

**Interviewer:** No worries, I won't tell.

**Frank:** So other things that I've done, I've been a tutor.

**Interviewer:** Yeah didn't you do the literacy tutoring?

**Frank:** Yeah.

**Interviewer:** I did that too when I was living in Hawai'i.

**Frank:** Is that right?

**Interviewer:** Yeah.

**Frank:** Great. You see a lot of, it's really good to see a person make progress from being functionally illiterate to being somewhat literate.

**Interviewer:** Yeah it makes a huge difference in their quality of life.

**Frank:** Oh yeah, huge difference. They notice things, they take a little more time taking it in, and they may act a little more appropriately. I also was a part time math teacher at [Community College] teaching introductory algebra course. What else did I do? I was also a teacher's aide at [Tech] in [City] helping students with their math problems and English and I felt great doing that, I really liked it. Didn't keep it up because I had my head problems, at least I felt good for a little while. Anything else?

**Interviewer:** Let me check my questions. What has had the greatest impact in your recovery?

**Frank:** What has had the greatest impact? I would say it was S.A. – Schizophrenics Anonymous. They have had the greatest impact. They really... it's not group therapy, which I've been through many times and in other situations, but this is the first time that it's really helped me cope better with my illness, with my diagnosis.

**Interviewer:** What do you think is behind that?

**Frank:** I think it, what's behind it, is that everyone else has ,outside of the facilitator, has the same problems that I have. Maybe not at the same degree of disability.

**Interviewer:** Or at the same time, you know?

**Frank:** Right, but they kind of have this ability to cover the gaps that we have with each other. If one has a problem and they can't seem to cope, another may be able to intervene.

**Interviewer:** I saw that last week, big time, with [Carl].

**Frank:** Yeah we do that all the time. And you know, when we first, when S.A. was started, I think it was in '91 or '92, we had a larger group and the group leader would assign buddies. One person would have a buddy or maybe two and these two other buddies would have the same kind of approach to solving problems, and the same kind of diagnosis so that if one of us had a problem we could discuss and we couldn't reach

CrisisCare or we couldn't reach our hospital, well then we could talk to them and you know they're there for us.

**Interviewer:** Kind of like a sponsor?

**Frank:** Right and you know it really does help to keep on a good keel and it's quicker than taking a trip to the hospital and waiting on the doctor for whenever he can see you.

**Interviewer:** It makes sense too, I mean, hospitals can be very helpful and I think you even said there were moments when the hospital really helped but they can also be scary and takes you out of the environment where you're really comfortable.

**Frank:** Right.

**Interviewer:** And if you can kind of talk through that issue or talk about what's going on with somebody else maybe you wouldn't have to go?

**Frank:** Right. Another thing that has changed since I've been mentally ill, it used to be that if you were destructive in society they would seclude you into a psychiatric ward but now it has to be either you're a harm to yourself or to somebody else and that's a good thing to some degree. But I think, too, there has to be another input, not input, there has to be another requirement on that, that if a person is disoriented that he should be hospitalized or at least be counseled in order to keep him calm.

**Interviewer:** Because sometimes it's hard to get into treatment right when you're not meeting those two qualifications. How did you get involved treatment? I mean we talked about sort of that initial getting sent to the hospital, but how did you get involved in your ongoing treatment?

**Frank:** Well, each time I was discharged from a psychiatric ward they would get me an appointment at the mental hygiene clinic over at the VA. And they would check with how my behavior has been at that point, as opposed to what it was when I was hospitalized, and the reason that I was hospitalized. That helps.

**Interviewer:** So do you have a constant number of providers at the VA or is it just you have the VA and it's a constant place to go and that is a comfortable place or what?

**Frank:** Well, we have a constant couple of providers, we have a psychologist and a psychiatrist and sometimes I do attend group therapy there. The other thing is that we have a help line sort of like CrisisCare here in [City], but the crisis line is just for veterans only and we have walk in clinics so that during the day if we cannot see our doctor then we can make a walk in appointment and they will see us as soon as they can. It's pretty nice.

**Interviewer:** Wow, yeah, that's pretty comprehensive.

**Frank:** Very.

**Interviewer:** Is there anything that you feel is missing from treatment right now for you or do you feel ...

**Frank:** No, I kind of got the whole nine yards now.

**Interviewer:** Good. All right, my last question: what would be important to know for someone who doesn't have schizophrenia about what it is like to live with schizophrenia?

**Frank:** One thing to know...

**Interviewer:** Or a couple of things? Whichever way you want to go.

**Frank:** We're not dumb. We're smart. We're smart. Sometimes we fool ourselves a little too much, but we're not stupid.

**Interviewer:** That's a big thing, I think.

**Frank:** Extremely.

**Interviewer:** I think a lot of times people presume incompetence, is what we call it, talking about it within the disability community. Everyone assumes that just because you're in a chair or you have to take medications that you're dumb and that's just...

**Frank:** Not true.

**Interviewer:** Untrue, really false.

**Frank:** Right, because, you know, of course, there's the film about the man who got the Nobel Peace Prize in Economics.

**Interviewer:** Yeah, a *Beautiful Mind*?

**Frank:** *Beautiful Mind*, but you know, that's a great, great encouragement for us. Repeat the question again, I've lost track.

**Interviewer:** What would be important to know for someone who doesn't have schizophrenia about what it is like to live with schizophrenia?

**Frank:** One of the things that it's like to live with schizophrenia is that it can be a 24-hour horror show. People's countenance will change. Their face will change – not the person with schizophrenia, but those around us their faces would change you know you've seen the TV program "Grimm"?

**Interviewer:** No.

**Frank:** You've haven't? Well if you get a chance to see it, this guy they call him a Grimm which means that he goes out and destroys evil characters, evil creatures.

**Interviewer:** So it's like a fairy tale?

**Frank:** Like a fairy tale, but see he has the ability to see these different creatures as they really are, but everybody else is just like you and me and in that way that's what schizophrenia is kind of like – in a way you see these kinds of things like that. Reality, reality isn't constant with us it changes quite a bit. I'm not saying that it's not normal to say that reality doesn't change, it does. But for us the consistency of reality doesn't jive. It doesn't. It somehow what makes sense for you, and I'm not saying anything about your thought process but what makes sense to you, the door here is on this side of the room the window is at the top of the room here but for us sometimes it's like maybe no door, maybe all wall or no window where it's this kind of thing where it's scary.

**Interviewer:** It's kind of like where reality overlaps for a lot of people, it sometimes feels like you're outside of that, that circle, there's something else there and it's very real to you.

**Frank:** Yeah.

**Interviewer:** You know, so it's hard for someone else to be like, "That's not real" because then would you trust me or would you not? It's really difficult.

**Frank:** That's another thing. Whether we could be trusted. You know, people say we ought to go out there and work because you got too much time on your hands I've tried to work and some problems that I've had when I'm not working.

**Interviewer:** And it's extra stress, too.

**Frank:** Yeah it is. But the thing is, what's the point? I mean if I'm making mistakes while I'm working, you know, there's somebody along the line that's going to get hurt if I make a product that isn't safe to use.

**Interviewer:** So there's a lot of pressure.

**Frank:** There's a lot of pressure. And you know we may make more mistakes than an average person does. Say if I was going to go work in an automotive factory putting



together a cruise control for a car, if I put it in wrong, or if I'm looking at the instructions and I have them point blank in front of me and I look down and I start putting together...

**Interviewer:** And one green light starts to look red or something like that.

**Frank:** Right. Or the mechanism that fits this way, goes in that way, you know? That's what I'm talking about.

**Interviewer:** That comes back again to a lot of that fear. That real concern.

**Frank:** Scary, scary. I think there's a program, a Star Trek program that came out years and years before that had a different kind of Earth. It's called "The Cage" and in it these aliens have captured the captain. They tried to get him to mate with a survivor of a spaceship crash and he finally gets a hold of one of the creatures, he's got him in a headlock, and the creature says, "Release me! Release me, or I'll tell your crew to blow up your ship." So that's kind of like another creature telling us these things, it's kind of like that, you know. We get too scared to do the right thing because we don't know what the right thing is all the time. Sometimes we do, but sometimes that just doesn't work. So another thing is trust. Problems with trust.

**Interviewer:** Problems trusting other people? Or problems with other people trusting you?

**Frank:** Both.

**Interviewer:** It sounds like a lot of the things are very isolating.

**Frank:** Yeah.

**Interviewer:** Some of the stuff you've talked about today has reflected that. The idea that you're worried about hurting other people or hurting yourself and so you kind of step out of the situation.

**Frank:** Yeah, you know not to react. It's strange because I was sitting out in the car, I was smoking a cigarette before I came in and there were a bunch of people walking around in the front of the library and I was looking at a pretty girl walking across the intersection and she had the light and out of the corner of my eye I was looking at the other people and they were looking at me and I'm thinking, "Well they know I have a mental illness somehow" or something so it makes me feel uncomfortable. That's why I isolate myself.

**Interviewer:** And it's hard too because it seems like it's easy for me to sit here and say, "Well how would they even know?" But if you're sitting with your reality, as we talked about, it's hard to figure that out because you feel like they know.

**Frank:** Right. Well after my first hospitalization in the Air Force a number of the soldiers, my comrades would ask, "Who was the doctor?" And I would say, "Dr. [X]." Well that was the first psychiatrist that I had and he was at the medical hospital and I'd say, "How did they know that?" Well okay, it's talk, it's gossip, so you know okay, it's cool. And then they'd start to say other things that I did or things that happened to me or what made happen and I thought how did they know all that? I mean maybe I don't mean to say that I'm being watched, because a lot of the stuff that I was doing was off base or it was at a place on the base way off where they don't know me that well so that's all going into that delusion. So I don't know what.

**Interviewer:** So you get contributory proof or confirmatory evidence all around?

**Frank:** Yeah.

**Interviewer:** Well, is there anything that we didn't talk about today that you want to make sure we do?

**Frank:** Keep us safe. We are your brother, your daughter, your son, your mother, your father, your grandfather your grandmother, your sister, your friend. We may not have all the tools in the tool box, but we do work with what we have and if you see us out there, of course you know we don't wear our disability out there like a tattoo on our bodies, so the thing to remember is that things that affect you don't affect us in the same way or in the same degree. I mean everyone has a different reaction, but schizophrenics, there's a typical type of reaction. So yeah we're family and friends.

**Interviewer:** It's a universal thing,

**Frank:** Yeah.

**Interviewer:** Well I really appreciate you meeting with me and I enjoyed our conversation. Thank you so much.

**Frank:** Sure, you're welcome.

**Interviewer:** Thank you.

(End of interview.)

### **Volunteer 3: Ethel**

**Interviewer:** If you wouldn't mind filling out this form. That's just the demographics, the questionnaire that I mentioned earlier.

**Ethel:** What's your ethnic?

**Interviewer:** That's if you identify as white, African-American, something else.

**Ethel:** Relationship status is what?

**Interviewer:** Single, married, divorce, separated, it's complicated

**Ethel:** It's complicated. [ineligible]

**Interviewer:** You have a what?

**Ethel:** I have a bachelor of science.

**Interviewer:** And you put B.S.? What is your bachelor's in?

**Ethel:** General studies, but there was actually a major in nutrition related science.

**Interviewer:** The nutrition related sciences?

**Ethel:** Food and nutrition related sciences.

**Interviewer:** Is that why you ended up being vegan? Because you learned too much about food?

**Ethel:** Well no, I actually didn't become vegan until after I joined the Seventh-Day Adventist church.

**Interviewer:** Oh, okay, yeah, I have a friend who is Seventh-Day Adventist and she's vegetarian, she's not vegan but she's vegetarian.

**Ethel:** Well I became vegan after I took the depression recovery class.

**Interviewer:** Oh okay, that was like last spring right? Because I think you guys were in it when I started with S.A.?

**Ethel:** Yeah I've been taking it for the past three years.

**Interviewer:** Oh, okay.

**Ethel:** So I'm becoming more and more stricter on my diet as I learn more.

**Interviewer:** Is that helping?

**Ethel:** Yeah, but well, my nurse practitioner, when I saw her last in person, she agreed to decrease the medicine, but then when I talked to the pharmacist and I also called the nurse at [CMHC], she decided not to decrease it and it probably was best because I went

from there to buying shoes and I couldn't walk and then when I did go walk and I walked the same distance and then like that toe swelled up then I couldn't walk and I haven't really been walking.

**Interviewer:** Yeah and that's important for your recovery right?

**Ethel:** It's important for my depression.

**Interviewer:** Yeah, gets you moving.

**Ethel:** Yeah and I have the [ineligible].

**Interviewer:** So it's probably an okay thing that that happens.

**Ethel:** Family composition, just one?

**Interviewer:** Yeah or are you the oldest in your family the youngest?

**Ethel:** I'm third.

**Interviewer:** Oh yeah? Out of how many?

**Ethel:** Four.

**Interviewer:** Oh my, so you're right there in the middle. Or you can also put that you live by yourself.

**Ethel:** Except it's been about 30 years since that's happened. Significant support?

**Interviewer:** Significant social support. So are there people in your life that are really important to you that are outside of your family.

**Ethel:** Well, I have a friend, [Fran].

**Interviewer:** How do you know [Fran]?

**Ethel:** Well, I met her in... was she? Well she was, she's 10 years older than me and she was, I don't know, she was in [Suburb] at the time, or I think she was in [Suburb] because I was living in [Suburb] and she was there for half the time that I met her and now she's living well I don't know if she's still in [Suburb] or if she's in [Suburb] but I still call her.

**Interviewer:** That's nice.

**Ethel:** And she's ten years older than me. She doesn't have any problems. She was a schoolteacher in an elementary school.

**Interviewer:** Oh, cool.

**Ethel:** I don't know why you need to tape this, this is only writing.

**Interviewer:** That's true. I figured I would just turn it on. When I transcribe it I'll just be like, "Long silence."

**Ethel:** You said the other one is affective schizophrenic?

**Interviewer:** There's schizoaffective and schizophrenia.

**Ethel:** No, but you said there's affective?

**Interviewer:** Yeah schizoaffective.

**Ethel:** Schizoaffective.

**Interviewer:** That's where you have more mood stuff with schizophrenia.

**Ethel:** I don't know about experiencing more mood stuff. I think I'm over my problems. I think I got the right medicine to take care of that.

**Interviewer:** Oh that's good.

**Ethel:** Well I put that for current mental health diagnosis. I don't know what my current mental health diagnosis is.

**Interviewer:** Oh okay.

**Ethel:** Maybe I should put depression.

**Interviewer:** Or is that a past one?

**Ethel:** I should say mild.

**Interviewer:** Okay. That's it.

**Ethel:** That's it?

**Interviewer:** Yeah. All right. I'll take that whole thing back. Okay, so thank you very much for filling all of that out. And I guess we'll just get started with the interview now. So my first question is when and how did you know you had schizophrenia or schizoaffective disorder?

**Ethel:** Well everybody told me.

**Interviewer:** Everybody told you?

**Ethel:** I was in college and I came out and I said that I was... this guy was going to come back and marry me and we went and got the pastor next door. I was living in this group home for Methodist students and then I went upstairs and put a facial mask on and the next thing I know the police were knocking on the door and I had this facial mask on.

**Interviewer:** Why were the police called?

**Ethel:** To take me to the hospital.

**Interviewer:** Do you know what you were doing for people to say that you needed to go to the hospital or do you not really remember?

**Ethel:** All I said was that this guy was going to come back and marry me. But see, the summer before, I was in a wedding and he came from Cyprus.

**Interviewer:** Oh the Greek islands? That's far.

**Ethel:** So that's how come they knew that I was not right.

**Interviewer:** So you had to go to the hospital with a facial mask on? When did you get a chance to wipe it off?

**Ethel:** After I got there.

**Interviewer:** So everybody around you thought that something was going on. Did you believe them or not believe them?

**Ethel:** Well, I didn't have any choice they ended up calling my dad and then he came up from [State] to [State]?

**Interviewer:** Oh, you were in [State] for school?

**Ethel:** Yeah.

**Interviewer:** How old were you?

**Ethel:** I was 20.

**Interviewer:** So you thought things were okay but everyone else around you was like?

**Ethel:** Well, I was taking biochemistry with medical students and graduate students, so I was glad to be relieved of that.

**Interviewer:** Going to the hospital is a good excuse for not going to class. What do you think about your diagnosis? Do you agree with it?

**Ethel:** Well, at the time I did, but since then with the medication, it's helped me and with all I've been through I've seen that I need all the help that I've got. It's been a long stressful period and the times when one time I, well, I've had a lot of fearful thoughts and in the hospitalization I had a lot of frightening thoughts and it's in the past it's very frightening and but now I'm all better.

**Interviewer:** It took some time to get to where you are now; did it take a lot of time to get comfortable with your diagnosis? Was there a time that you didn't believe people that you had your diagnosis?

**Ethel:** Well the medication was a hard time getting on because they didn't have the right medication for me. And then it wasn't until 2006 when I prayed all year and then it was the next year that they came out with the right medicine for me.

**Interviewer:** So it wasn't until they came out with the right medication that you felt you had the right meds? That's a long time to have those fearful thoughts and to just not feel right.

**Ethel:** Yeah I was in and out of the hospital every year.

**Interviewer:** Yeah so it wasn't until 2006 when you prayed and it was the next year they came out with the right medication. So how often have you been in the hospital since 2007?

**Ethel:** 2006 was the last time and then I got the medicine in 2007 as an outpatient and then I hadn't been in the hospital again until June of 2011.

**Interviewer:** Wow that's a long time to go from going to the hospital every year to not going to the hospital for four years. Wow.

**Ethel:** That's four and a half years.

**Interviewer:** I remember you were in the hospital last year. People at S.A. prayed for you. So how did you family and friends react to your diagnosis?

**Ethel:** They insisted that I always had to take my medicine even though it wasn't working.

**Interviewer:** Did they believe you when you said that it's not working?

**Ethel:** They just said that you're not going to get better and so that's what encouraged me to pray all year.

**Interviewer:** So your friends and family said "Keep taking your medication." And you said, "Well it's not working." And they said, "Well then you're just not going to get better"? So what kept you hopeful that you would get better?

**Ethel:** The grace of God and the Scriptures.

**Interviewer:** How did you get involved in treatment?

**Ethel:** Well when I was going to [County] Memorial Hospital I got a psychologist that, he was related to the people with the Seventh-Day Adventist Church, and he gave me hope and [ineligible] and the Seventh-Day Adventist Church and then I got a family doctor with the SDA church and the relationships and the church.

**Interviewer:** So it was really through your spiritual community that you found a lot of hope?

**Ethel:** Yes.

**Interviewer:** And also through the social support, it sounds like the relationships with people who got your involved with SDA? And kept you involved, too, I bet.

**Ethel:** Yes.

**Interviewer:** So how do you define recovery?

**Ethel:** Well, I define recovery by having a relationship with God and salvation through God. I do not find it necessarily through my nurse practitioner because she doesn't understand me as much as God understands me and gives me hope.

**Interviewer:** So recovery is through your faith? Why do you keep going to the nurse practitioner?

**Ethel:** To get my medicine.

**Interviewer:** Is medicine also important to recovery? How do you view medicine?

**Ethel:** The medicine I am on now is because I believe that God created it because I prayed that whole year and then it came out.

**Interviewer:** So you see medication coming from, you have to get it from your nurse practitioner, but where do you see it coming from? From God answering prayers?

**Ethel:** Yeah, if you pray for it, you can get it.

**Interviewer:** What medication is the new one that came out?

**Ethel:** Invega.

**Interviewer:** Oh, Invega. I've heard positive things about Invega. So it made the big difference for you?

**Ethel:** Yes.

**Interviewer:** so I know we've talked about it, but the role that medication plays in your recovery is?

**Ethel:** It's a big role.

**Interviewer:** Big role, not the central one it sounds like for you, the biggest one is your relationship with God?

**Ethel:** It is the biggest. If it wasn't for God, well my relationship with God is what keeps me going, what keeps me from getting depressed and down and keeps my spirit up.

**Interviewer:** So your relationship with God is what keeps you going and the medications help with?

**Ethel:** Keeps my thinking right.

**Interviewer:** Keeps you kind of on the path?

**Ethel:** It keeps my mind clear.

**Interviewer:** So what has had the greatest impact on your recovery?

**Ethel:** The medication and also my diet. You know working with depression, besides schizophrenia, and walking, getting out, and walking that has helped a great deal. I've lost a lot of weight. I've not been walking recently.

**Interviewer:** Is your toe feeling better? I know last week you said it was swollen, is it better now?

**Ethel:** Yeah it's better now.

**Interviewer:** That's good are you going to start walking again?

**Ethel:** Yeah.

**Interviewer:** Tell me a little bit about what diet does for your depression?

**Ethel:** Well you have to get tryptophan and omega-3 and B-12 and B-6. They all work together and one of them helps make serotonin, which helps with the sunlight and keeps your mood up.

**Interviewer:** So what do you eat a lot of to keep that serotonin up?

**Ethel:** Flaxseed and sunflower seeds and walnuts and almonds and I have almond butter sometimes and I have lentils and navy beans.

**Interviewer:** Sounds pretty good. Sounds like one way to keep yourself healthy is to manage your diet and do exercise. Do you sleep enough?

**Ethel:** No. Right now I'm sleeping too much. But I need it right now because I'm depressed

**Interviewer:** Oh yeah? When your sleep gets off do you noticed that you get more depressed?

**Ethel:** Yeah I had a seizure on Thursday morning of last week and bruised my arm.

**Interviewer:** Oh my gosh!

**Ethel:** And I got one on my leg.

**Interviewer:** And were you by yourself?

**Ethel:** I got up at 4:30 to scrub the floors.

**Interviewer:** Oh dear! And you had a seizure then?

**Ethel:** I knocked over the bucket.

**Interviewer:** That's intense. How's your arm?

**Ethel:** It's all right.

**Interviewer:** Is that part of the reason you're not feeling so good, that you're depressed?

**Ethel:** No, I got up and started scrubbing the floors again.

**Interviewer:** No medical attention?

**Ethel:** No.

**Interviewer:** Oh dear, I didn't know you had seizures.

**Ethel:** Yes.

**Interviewer:** How often do you have them?

**Ethel:** I usually have them in my sleep but that was a time I should have been sleeping and if I had been sleeping I probably wouldn't have had it.

**Interviewer:** Are you on any kind of medication for that?

**Ethel:** Yeah.

**Interviewer:** Seizures can be kind of serious; I mean that bruise is intense.

**Ethel:** It's healing that's why it's so colored.

**Interviewer:** So how long did it take you to get comfortable, well how long did it take you to know that you needed to take medications regularly?

**Ethel:** Well when you're around my family it doesn't take long at all. They're insistent about it.

**Interviewer:** Do you feel like you still need them to be around to encourage you to take your medications? Or do you feel like now you are your own motivator?

**Ethel:** Yeah.

**Interviewer:** Was it that finally in 2007 the new medication came out?

**Ethel:** No, I continued to take them because they were always after me even though they weren't working.

**Interviewer:** Well I'm wondering kind of when you realized for yourself that you needed to take them?

**Ethel:** When it worked in 2007. I knew that it was working.

**Interviewer:** So it took a really long time. You were forced to take medications by your family and by doctors and stuff, and then finally when it was effective, you were like, "Oh okay," because there's a big difference between someone telling you that you have to do something and then you telling yourself that you need to do something? Was that that difference then?

**Ethel:** Well there's a difference when you know it's working and when you know it's not.

**Interviewer:** Yeah, you said that it clears up your mind and thoughts. What was happening to you before the medications worked?

**Ethel:** Well it always put me back in the hospital in spite of me taking them.

**Interviewer:** How were the hospital experiences? Were they good? Bad? Mixed?

**Ethel:** Oh, they were okay, I'll put it that way. But you see, you're without a career though, and I needed to get educated. I've lost my education. All the medicine just wiped out all my memory and the education that I had and it's it seems like a big waste.

**Interviewer:** I bet that's really frustrating especially at that time when you had the education and you had to take the medication even though you knew it wasn't working and it just got in your way and erases all that knowledge.

**Ethel:** Yeah, but I tried to reeducate myself and I'm thinking about going to the library and seeing if I can get a job there.

**Interviewer:** That would be nice, you could get a lot of reading done.

**Ethel:** Yeah that way if I had to heal up from a sore toe I wouldn't have that much walking to do.

**Interviewer:** It sounds like with your depression recovery class and being more informed about food, especially you know since you're a vegan you have to know how to get all your amino acids and protein, it sounds like you're using some of that education that you already had. Do you feel like it has come back to you?

**Ethel:** Well I had gotten newsletters in the mail and I've gotten a lot of books that help me.

**Interviewer:** That's good. So my last question is what would be important for people who don't have schizoaffective disorder to know about what it is like to live with schizoaffective disorder?

**Ethel:** Really to some extent people with schizoaffective disorder, they need assistance with everyday life. Depends upon if they have seizures, of course, they need help with driving and getting places but it depends upon how much education they have to know how much they can help themselves. Now my one insurance she told me when I get my, and I've been doing this on my own, when I get my information on my family and job and family services job and family services whatever.

**Interviewer:** JFS?

**Ethel:** Yeah to call them and they would help me with filling that out, which I've been doing that before and filling it out on my own but I don't know how much they're going to help me. You know [Rebecca]'s mom says that [Rebecca] doesn't know how to do that. Her mom always has to help her in doing that. But sometimes I have questions about everyday life, and well, I can usually ask friends about questions if I have any questions.

**Interviewer:** Well that's a form of assistance, it's just different from a case manager or insurance. It sounds like what you're saying is that you do need assistance with certain things and that people what people need is different from person to person. Do you feel like it's sometimes hard to ask for assistance or to get assistance?

**Ethel:** It might be hard to explain what you need.

**Interviewer:** Is there anything else that you would like people to know about what it is like to live with schizoaffective disorder?

**Ethel:** Well with me you have to learn how to walk.

**Interviewer:** What do you mean? Because you can't drive?

**Ethel:** Yeah I was going to go to the grocery store this morning but I wanted to make sure I was back for our meeting so I'll go later this afternoon.

**Interviewer:** Well I really appreciate you talking with me about your life experiences and what it means to take medication and to do recovery. I appreciate it.



**Ethel:** Okay, you're welcome.

**Interviewer:** Any last words of wisdom?

**Ethel:** Well I guess just listen to the patients and see what they have to say and that doctors don't understand everything.

**Interviewer:** Do you think it's because it's sometimes hard to get people to trust that you know what you need?

**Ethel:** Yeah, but then again, they might know better.

**Interviewer:** Sometimes that happens too, but I like that message of just listen because I think a lot of times people don't get heard.

**Ethel:** Yeah.

**Interviewer:** All right well I think that's it for our interview. Thank you!

(End of interview.)

**Volunteer 4: Earl**

**Interviewer:** There we go. I'm going to have you fill out this form.

**Earl:** 61.

**Interviewer:** That young?

**Earl:** Yeah, my dad's 90.

**Interviewer:** I know he's getting up there. Is he at work today?

**Earl:** Yeah. Relationships status? What does that mean?

**Interviewer:** Single, married, divorced, separated, it's complicated.

**Earl:** I've never had.

**Interviewer:** That means single?

**Earl:** Yeah. Did you come up the hill as you came up here?

**Interviewer:** I don't this so. Do you mean the hill coming up past the school?

**Earl:** Yeah.

**Interviewer:** I saw that was being torn down.

**Earl:** Yeah that used to be an all girls' school. All girls Catholic high school.

**Interviewer:** Yeah.

**Earl:** Highest level of education?

**Interviewer:** High school grad, some college, college, master's degree, Second grade...

**Earl:** B.A.

**Interviewer:** What's your B.A. in?

**Earl:** Philosophy. And yeah, philosophy, a B.A. in philosophy.

**Interviewer:** From where?

**Earl:** St. [X's]. I was in seminary there.

**Interviewer:** I knew you were in seminary. Family composition means who is in your family.

**Earl:** Oh. There's six of us.

**Interviewer:** Six children or six people total in your family?

**Earl:** Six total.

**Interviewer:** Are you the youngest, oldest, somewhere in the middle?

**Earl:** I'm the eldest.

**Interviewer:** Oldest of Earl?

**Earl:** Oldest of five.

**Interviewer:** Oh did someone pass away?

**Earl:** No, the six isn't including me. Significant social support? I have some cousins who are dead.

**Interviewer:** I remember you sharing that someone had passed away recently.

**Earl:** Yeah I have an aunt who died. She was a nun. I felt close to her.

**Interviewer:** Your significant social support is...

**Earl:** She had a tumor. Significant social support what is that?

**Interviewer:** Are there people you talk to regularly any close friends?

**Earl:** S.A.

**Interviewer:** That's a good one.

**Earl:** Catholic Church.

**Interviewer:** Do you go to the Church over there?

**Earl:** No.

**Interviewer:** Is that a Catholic Church?

**Earl:** Yeah, but we go to Our Lady of the Rosary now. Mom went to work at the parish rectory for a good number of years so she decided to join that parish.

**Interviewer:** Yeah that makes sense. Do you have any military background?

**Earl:** (laughter)

**Interviewer:** What are you laughing for? Is the answer no?

**Earl:** N/A. What is my current mental health diagnosis?

**Interviewer:** I don't know, that's why I'm asking you.

**Earl:** Can I put a question mark?

**Interviewer:** Yes.

**Earl:** Previous?

**Interviewer:** Do you know any of your diagnoses from the past?

**Earl:** Oh, yes I do.

**Interviewer:** Do you want to list them off and I can write them down for you or do you want to keep going?

**Earl:** I have to think about them. Can I bring them to the meeting tomorrow night?

**Interviewer:** Maybe.

**Earl:** They're at the tip of my tongue too.

**Interviewer:** Thank you again for filling all of that stuff out.

**Earl:** I'm sorry it took so long.

**Interviewer:** Oh no, no.

**Earl:** Just a little concerned with some of those questions that I couldn't remember.

**Interviewer:** Yeah that's all right. Here we go.

**Earl:** They're closely related too.

**Interviewer:** Do you mean schizophrenia and schizoaffective?

**Earl:** Schizoaffective.

**Interviewer:** Is that your current diagnosis or a past one?

**Earl:** Schizophrenia, schizoaffective. Schizoaffective is the latest one.

**Interviewer:** Do you want me to write that down on your form?

**Earl:** Right now I'm taking Lithium, which makes me drool as you can see.

**Interviewer:** Some of those side effects.

**Earl:** Yeah, awful.

**Interviewer:** Yeah they can be no fun.

**Earl:** Embarrassing.

**Interviewer:** That's all right, I've seen worse. All right, when and how did you know you had schizophrenia or schizoaffective disorder?

**Earl:** Probably from Dr. [X] out at the hospital at St. [X's].

**Interviewer:** Was that your first hospitalization?

**Earl:** Heck, I don't know when he said the words schizophrenia. I don't know when he said I had schizoaffective. I don't remember. I just remember the word schizoaffective but I don't remember when he said that.

**Interviewer:** How often have you seen this doctor?

**Earl:** Dr. [X]? I saw him for a number of years and I went up here to see doctors at [Hospital] and I'm trying to remember the names of the doctors up here.

**Interviewer:** When did you first know that you had a mental illness? Did someone have to tell you or did you just feel that you had something going on?

**Earl:** Well, we always had trouble in our family with my uncle. He was a barber over here on Main Street. And he liked to play musical instruments, barber, and make sure his family was provided for.

**Interviewer:** Sounds like an interesting guy.

**Earl:** Yes. Had a fiddle, sax, and came to the farm. I don't know what lead to his illness, but my illness, what the heck, what happened to me?

**Interviewer:** Is it hard to remember or are you just not sure?

**Earl:** I'm not sure anymore, when dad put me in the... in the...

**Interviewer:** Hospital?

**Earl:** St. [X's].

**Interviewer:** What do you think about your diagnosis? Do you agree with it?

**Earl:** Well at [X] Hospital they talked about my diagnoses as being about split personality.

**Interviewer:** What did you think of that?

**Earl:** It's an interesting one but schizoaffective makes more sense than split personality.

**Interviewer:** do you think schizoaffective disorder is an accurate diagnosis for you?

**Earl:** I need to study it more to see what kind of an update it is on schizophrenia because schizophrenia in those days was an altogether different thing than it is today.

**Interviewer:** Yeah that's true, with each *DSM*, sometimes the definitions change.

**Earl:** Yeah, I know what that is. That's the diagnostic...

**Interviewer:** Statistical, the *Diagnostic and Statistical Manual*. So how did your family and friends react when you got sick?

**Earl:** The friends I had, peer groups in the past, guys I ran cross country with, and tried to play baseball with, the guys I hung out with, and tried to play basketball with, and I had no real talents for that. The beer drinkers, you know they quit hanging out with me. The guys I went to school with up at college the guys I went to town with at [Bar].

**Interviewer:** [Bar]?

**Earl:** Yeah. The beer drinkers. I didn't, you know, I just didn't hear from them anymore.

**Interviewer:** Yeah, so they kind of just disappeared?

**Earl:** Guys here in [City] who were up there, they disappeared. They married. Yeah, I know one guy who lives over here on Bridge Avenue; he hasn't seen me in years. So I haven't seen him or he hasn't seen me in years. Maybe that's better.

**Interviewer:** How did your family react?

**Earl:** Well I have a sister who is a baseball player at [High School], they keep me in touch with their son who plays baseball. I played baseball and I have an interest in baseball. Some interest in baseball.

**Interviewer:** It's a good game.

**Earl:** Yeah it's a good game if you like to drink beer.

**Interviewer:** And play ball!

**Earl:** And watch it on TV and keep an eye on it in the newspaper. Statistical.

**Interviewer:** Yeah, statistical analysis. Baseball has a lot of stats.

**Earl:** Yes it does, that's what I did in high school I did stats for the basketball.

**Interviewer:** Kept track of what everybody was shooting?

**Earl:** Yeah.

**Interviewer:** So you keep in touch with your family?

**Earl:** Yeah.

**Interviewer:** You have a lot of siblings.

**Earl:** Yeah, my sister is in danger of death right now.

**Interviewer:** Yeah, how's she doing?

**Earl:** She was in the hospital over the weekend. She didn't make it to my mom and my dad's party.

**Interviewer:** Aw, that's too bad.

**Earl:** She's going to hang in there if she keeps her kidney. She has two kidneys right now.

**Interviewer:** She just needs one.

**Earl:** Yeah, she just needs one but the second, well, the one has a stent in it and they are trying to save that one but it may be that they take it and she won't be able to keep the one with the stent and they'll have to take it out and then she would only have the one and that would make it harder for her.

**Interviewer:** Well, I hope she recovers, I hope she gets better.

**Earl:** Thank you.

**Interviewer:** She's a very sweet lady.

**Earl:** You've seen her?

**Interviewer:** Yeah, she came to S.A. a few times.

**Earl:** Oh yeah.

**Interviewer:** Yeah, she's very nice.

**Earl:** Ah, I got to tell her you say hi.

**Interviewer:** Yeah. So how did you get involved in treatment? What was your first interaction with treatment?

**Earl:** Oh well, well, that's what got me in my first involvement in mental health therapy. I was going to be an interceptor pilot. A sky pilot. I was driving down. Mom was at the office at

Church and I went over there to see how she was doing to see if I could help her if there was anything I could get for her then she said, "Oh, guy by the name of [Larry] was in here today and why don't you go over there to [CMHC] on [Street], maybe he can help counsel you."

**Interviewer:** Oh okay, so it was a suggestion, you weren't forced to?

**Earl:** I wasn't forced to, and it was something that I might be able to go to. I wasn't working at the time. I was driving up around north of the city looking for work at the farm.

**Interviewer:** So you got involved in treatment through your mom knowing someone and just kind of suggesting that you go?

**Earl:** Go see [Larry]. It was just like a fish and the bait. And when I went to see [Larry] he said you go see [Joe], wait was the guy's name [Joe]? Dr. some guy named Dr. [Joe].

**Interviewer:** So you went to go see Larry and he suggested that you go see the psychiatrist?

**Earl:** Yes.

**Interviewer:** So that's how you got involved?

**Earl:** And the doctor says you go over to [Hospital] or go over to St. [X's].

**Interviewer:** So you got stepped through the whole system?

**Earl:** Yeah.

**Interviewer:** So you got hospitalized that day? Or later around then?

**Earl:** Later that afternoon instead of being a sky pilot, an interceptor pilot. I got shot down.

**Interviewer:** Metaphorically. Okay, so that's how you got involved. So you just walked in there and all of a sudden you were in the hospital. How did that feel?

**Earl:** I felt dejected, but well, I'd been through it before with trying out for basketball.

**Interviewer:** So it was another disappointment for you?

**Earl:** Yes, it seemed like all they wanted me to do was be involved in things like seminary. Seminary was important but it was stuff that was tough stuff to do and you can't do nothing. That's you can't do most guys would see that as something that you can't have any fun doing and I thought well that's, I had a priest that tell me about fulfillment. And hey, you get to drink, you get to drink beer.

**Interviewer:** You get to help people?

**Earl:** Yes.

**Interviewer:** You know I think for some people that is fulfillment and for some people it's not?

**Earl:** Yes, it is.

**Interviewer:** Or else we would all be priests right?

**Earl:** Yeah they said in the Bible about that and I'm over here with priests at the parish down here when I was down at [Catholic Church] and having the, or have found faith and the women who found things hard to do are going in their lives. I found some people last night who liked being around me. Some of the women.

**Interviewer:** That's nice was that over at church?

**Earl:** Yeah.

**Interviewer:** It's important to find people who enjoy being around you and who you enjoy being around.

**Earl:** Yeah might be some of the ones who may be married I don't know you know I didn't, you know I liked them. We were just close.

**Interviewer:** So I wonder how do you define recovery?

**Earl:** Recuperative reflection.

**Interviewer:** Recuperative reflection? How do you define recuperative reflection?

**Earl:** It's an old idea of philosophy.

**Interviewer:** So I mean what does that mean?

**Earl:** Well my friend, Father [Bob], who died this last fall, was only 80 some years old. He was a missionary.

**Interviewer:** Where all did he go?

**Earl:** Peru.

**Interviewer:** Very cool.

**Earl:** And with the alpacas. He led a hard life.

**Interviewer:** I bet. So was he the person who taught you about recuperative reflection and philosophy?

**Earl:** Yeah.

**Interviewer:** So what role does medication plays in your recovery?

**Earl:** What role does medication?

**Interviewer:** What role does medication play in your recovery? Or in your life?

**Earl:** It's enlightening.

**Interviewer:** How so?

**Earl:** Keeps me alert. Helps keep me alert. It may not be the only thing that keeps me alert. Coffee helps, too.

**Interviewer:** Does it help clear things up for you?

**Earl:** Yeah.

**Interviewer:** Do you take your medication all the time as the doctor recommends, or do you sometimes forget?

**Earl:** Yeah, I was just trying to think if I took my nine o'clock meds. Yes.

**Interviewer:** Well, it's a little after nine now.

**Earl:** Yeah well.

**Interviewer:** Do you want to take them now?

**Earl:** How far do we have to go?

**Interviewer:** Well I only have two more questions, but if you want to take a break we can.

**Earl:** No, no, go on.

**Interviewer:** So we were talking about recovery and I'm wondering, what has had the greatest impact in your recovery? What's been the most helpful thing?

**Earl:** Well, my parents, my mom living between St. [X] and Fort Recovery.

**Interviewer:** So your parents have been helpful in your recovery?

**Earl:** Yeah and my grandma and grandpa living in St. [X] and Fort Recovery on the farm.

**Interviewer:** So that's had the best impact on your recovery?

**Earl:** Yeah I had a girlfriend between Mrs. [G] up at St. [X] College and her name was [Debby B]. Do you know that family?

**Interviewer:** Nope.

**Earl:** Well, they're the bowling pin and sporting equipment family. Well, she was a nice looking girl up there and caught my eye but she already had a boyfriend.

**Interviewer:** So you missed your chance?

**Earl:** Yeah, I also knew a guy named [Keith] from up there and he was a seminarian and he was a pro-life, he was the head of pro-life up in that county. He's a big wheel up in Washington DC in the march for life in January. There were a hundred thousand people and him.

**Interviewer:** My last question is what would be important for people without schizophrenia to know about what it is like to live with schizophrenia or schizoaffective disorder?

**Earl:** What can they know?

**Interviewer:** What's the most important thing you want people to know about what it's like to live with schizoaffective disorder?

**Earl:** Don't. Don't. There was the idea that they gave me two guys two weeks ago in the group and I forgot to write it down but I got this idea from some guy in Michigan and when they heard me say it. It stayed in their minds but I forget what that guy in Michigan had said, don't, don't give up, just don't give up.

**Interviewer:** Are you trying to remember... we were talking about choosing to live and it was suicide is a permanent answer to a temporary problem, was it something like that?

**Earl:** Yeah, choosing to live.

**Interviewer:** But kind of your message is that you don't want to give up you want to keep living keep working keep going?

**Earl:** Yeah, choosing to live not give into a temporary problem.

**Interviewer:** Was there anything else that we didn't talk about today that you want to make sure we talk about?

**Earl:** No.

**Interviewer:** Well that concludes our interview. Thank you very much.

(End of interview.)

#### **Volunteer 5: Donna**

**Interviewer:** This is a demographics form. It's just asking kind of basic background information.

**Donna:** Okay.

**Interviewer:** If you have any questions, you can let me know.

**Donna:** It's okay.

**Interviewer:** Yeah I used the word "family composition" and that's awkward. So it basically means who is in your family.

**Donna:** Do you want me to write this down?

**Interviewer:** Yeah.

**Donna:** Oh, okay. I thought you were going to ask me. What's ethnicity?

**Interviewer:** Are you white, African-American, Asian?

**Donna:** What's relationship status?

**Interviewer:** Single, married, divorce, it's complicated.

**Donna:** It is complicated. So for my family do I put mom, dad, brother?

**Interviewer:** Yeah, you can answer it how ever you want.

**Donna:** Okay. So would that be S.A. or Community Mental Health Center?

**Interviewer:** Yeah, whatever you consider to be important social resources for you.

**Donna:** Oh, let's see, what else, just around my apartment complex.

**Interviewer:** Neighbors.

**Donna:** Yeah. No military background. For religion I'm going to say Adventist.

**Interviewer:** Seventh-day Adventist?

**Donna:** Yes.

**Interviewer:** Do you go to the same church as [Ethel]?

**Donna:** Yeah, but no, there's one in [Suburb] and there's one in [Another Suburb]. I go to the one in [Another Suburb] and she goes to the one in [Suburb]. Let's see current mental health diagnosis? How do you spell schizophrenia?

**Interviewer:** s-c-h-i-z-o-p-h-r-e-n-i-a

**Donna:** Gosh.

**Interviewer:** It's a long one, right?

**Donna:** Yes. Other health concerns? Do you mean physically?

**Interviewer:** Yeah if you want to put those down.

**Donna:** Okay. The only two things I'm concerned about are my arthritis and my wrist that I broke a while ago. Okay, here you go.

**Interviewer:** I appreciate that. All right, now onto the formal interview process. So my first question is when and how did you know that you have schizophrenia?

**Donna:** Um.

**Interviewer:** Long story?

**Donna:** I never knew I had it until, let's see, I was 19 when I was diagnosed and then I was 50-something when I started to realize it. I kept saying, "What's wrong with me? What's going on?" and no body could tell me. Well, I said I'm not leaving the hospital without knowing but I did.

**Interviewer:** So no one at the hospital ever told you?

**Donna:** No, no.

**Interviewer:** What did they say? Did they say anything about your diagnosis or why you were there?

**Donna:** No, no.

**Interviewer:** So for like 30 something years?

**Donna:** [H] hospital.

**Interviewer:** So when you were first diagnosed at 19, did anyone tell you?

**Donna:** No.

**Interviewer:** How do you know then that you were diagnosed at 19?

**Donna:** Oh I'll tell you why. This is kind of, you may not like me very much after this, but I got pregnant and I was sitting there talking to a doctor for an abortion and I saw on a paper that he had my name down as paranoid schizophrenic. Yeah. And I saw that and that's when I thought that I was diagnosed. That's the only way I knew.

**Interviewer:** Oh my gosh. That was at age 19?

**Donna:** Yeah.

**Interviewer:** So it wasn't even a psychiatrist, it was a medical doctor that you were seeing for a medical procedure?

**Donna:** Yeah my psychiatrist sent him over some information about me.

**Interviewer:** Oh so you had been meeting with a psychiatrist. Were you on medications?

**Donna:** Yes.

**Interviewer:** And you had no idea why?

**Donna:** No, no.

**Interviewer:** Wow.

**Donna:** They never told me anything.



**Interviewer:** That feels really wrong.

**Donna:** Yeah, it was wrong.

**Interviewer:** So you just found out by coincidence what your diagnosis had been?

**Donna:** I just can't remember what happened or when. It was in my 50s, I think, when I knew I was paranoid schizophrenic, maybe when I started coming here maybe, but I'm not sure.

**Interviewer:** So it was sometime in your 50s when you were like, "Okay. This diagnosis makes sense, this is what's going on"?

**Donna:** Yeah, yes.

**Interviewer:** Can you think of was there anything did you change medications at the time or had you started to see a new doctor? Or had you started to come to S.A. and thought well this makes sense?

**Donna:** I think S.A.

**Interviewer:** How did you end up starting to come to S.A.?

**Donna:** My doctor told me about it, and he said, "I want you to go to S.A." So I called and found out where they were located.

**Interviewer:** So coming here. That's big.

**Donna:** I know. I started thinking about being, maybe I'm a schizophrenic in my 50s, my 40s or 50s and I don't know why. I know I was coming here, maybe that was it. I don't know

**Interviewer:** So for all of that time when you were, you found out what your diagnosis was from the psychiatrist when you were 19 and only started to identify that way in...

**Donna:** Well, no one told me I was paranoid schizophrenic.

**Interviewer:** Yeah you found out by accident?

**Donna:** Yeah, go ahead.

**Interviewer:** So were you taking medication that whole time?

**Donna:** Yeah.

**Interviewer:** Did you know why you were taking medications?

**Donna:** No.

**Interviewer:** Was it just like, "They told me I had to so here I am"?

**Donna:** Yeah, they told me I had to, so here I am.

**Interviewer:** Did you take them consistently or not consistently?

**Donna:** Consistently. And I went to bed, and went to bed, the medicine made me so tired. It was Metaril and they forced me, they pulled me out of bed, they pushed me down to the group. The arts and crafts group. And I ate meals and everything, but I never knew what was wrong with me.

**Interviewer:** How long were you in the hospital?

**Donna:** I was there for three months. I got out I went back for three months. I got out I was back for two months. I got out three months. In an out for six times because they never told me what was wrong with me.

**Interviewer:** So you can never really get recovered then?

**Donna:** Yeah.

**Interviewer:** Do you agree with your diagnosis now? What do you think about it?

**Donna:** If they had told me sooner, I would be better. But they didn't tell me sooner, so now it's like I have these thoughts and sometimes they are real to me, and my therapist told me to pretend she's there telling me that it's not all about me. "Pretend I'm telling

you that you no special powers or more special powers than anyone else.” That’s the main thing that I have no more special powers than anybody else.

**Interviewer:** So did you get told that that’s grandiose delusions?

**Donna:** No, nobody told me that. I read it. I read it.

**Interviewer:** You had to learn about it yourself.

**Donna:** Yeah, yeah, nobody would tell me.

**Interviewer:** How did your friends and family react to your mental illness, to your diagnosis?

**Donna:** My dad was guilt and guilt. My mom was guilt and guilt.

**Interviewer:** Like blaming you? Or did they feel guilty themselves?

**Donna:** Themselves.

**Interviewer:** Okay.

**Donna:** And they my dad never missed a weekend coming to see me in [City] at [H] hospital.

**Interviewer:** Oh, that’s nice.

**Donna:** Yeah. My brother was in jail up there and we lived together for a while and I moved out and went down to [State] University campus and he stayed in the apartment. And what was the question?

**Interviewer:** How did your friends and family react?

**Donna:** Oh, my dad kept coming to see my brother and I every Saturday and Sunday, no, I mean every Saturday or Sunday. And my brother got into scientology and that’s how he got better. But I never got better. I was in and out of there six times and he was only in there once.

**Interviewer:** So your brother has a mental illness as well or was he just in jail?

**Donna:** No, he recovered with scientology.

**Interviewer:** Did you have friends when you first got sick?

**Donna:** Yeah I had friends in the hospital.

**Interviewer:** Do you still keep in touch with them?

**Donna:** No. I was a teenager and me and this other girl shared the same room and we had a ball. She kept singing, “war what is it good for.”

**Interviewer:** Did she do the “uh” at the end?

**Donna:** Yes, that’s what she did most of all and it was funny. It was so funny.

**Interviewer:** So how did you first get involved in treatment?

**Donna:** My dad and mom got a mental inquest warrant.

**Interviewer:** I’ve never heard of that before. What is that?

**Donna:** Well, if you get a psychiatrist to tell the police that you are mentally ill, they will come and take you to the hospital.

**Interviewer:** Oh is that the formal name of the ‘pink slip’?

**Donna:** Yeah.

**Interviewer:** Okay. So your parents got that when you were 19?

**Donna:** Yeah, they asked me if I wanted to go see my brother and I said, “Yeah” and I rode up with them and then talked to a psychiatrist and they told me they wanted me to talk to a psychiatrist, all sneaky you know.

**Interviewer:** Yeah it’s sounds a little sneaky.

**Donna:** Yeah sneaky. And I talked to a psychiatrist and they said I think you should stay here a couple weeks and I said, “No, I’m not staying here a couple weeks.” So they took

me home and then they got the mental inquest. And the police came and took me to [Local] Hospital – fifth floor of [Local] Hospital. And I thought everyone knew my thoughts, and can you imagine that?

**Interviewer:** That's scary; you would never have a private moment.

**Donna:** This guy goes, "I wish you had told me that." And I go, "Well, I thought you knew since you knew all my thoughts." He goes, "Oh." He was nice.

**Interviewer:** Was that someone in the hospital?

**Donna:** Yeah.

**Interviewer:** So that was your first interaction with the mental health system. Was there a time when you started to seek out mental health services voluntarily?

**Donna:** No. Oh, well, yes, when I was in my 50s.

**Interviewer:** Yeah, later when you decided that this was the diagnosis that makes sense?

**Donna:** Yeah. I went in because it made sense to me to go in.

**Interviewer:** So for the longest time it was involuntary hospitalizations and taking meds because you had to?

**Donna:** Yeah. Well they were all voluntary after the first one.

**Interviewer:** So did you go by yourself or did someone take you there and you signed yourself in voluntarily?

**Donna:** Yeah, my dad took me. This one girl told me, "You got to go into the hospital" and I said, "No. I don't." So I called my dad and asked him if I should go to the hospital and he said yeah. And you know six times I forget.

**Interviewer:** So it sounds like somebody said you might need some help and eventually you were like, "Okay, yeah"?

**Donna:** Yeah.

**Interviewer:** So you voluntarily decided to start seeking treatment later when you learned more about your diagnosis?

**Donna:** When I was when I went to [K] hospital the doctor put me on clozaril and that helped keep me sane, but my white blood cells went up and I couldn't take it anymore. If I could take clozaril, believe me I would. It helped.

**Interviewer:** So you still can't take it because of the white blood cell count. What are you on now?

**Donna:** A lot. Well. Saffress, elavil, diazepam, cymbalta, prilosec, synthroid, neurotin. That's about it.

**Interviewer:** That's a handful. Are they helping you at all?

**Donna:** Yeah especially with the pain in my knees. But what did I have to tell you? Uh. Oh I don't think I need to have surgery on my knee.

**Interviewer:** Is that what the doctors are suggesting as a possibility?

**Donna:** He did, but I don't want to.

**Interviewer:** Yeah, that's a hard recovery.

**Donna:** Yeah, well, I talked to him again and he said well we want to avoid surgery like that and I thought maybe he thinks I don't need to.

**Interviewer:** Sometimes it's hard for them to make up their minds.

**Donna:** Yeah it hurts though.

**Interviewer:** No fun.

**Donna:** Yeah.

**Interviewer:** So you got involved in treatment involuntarily but started going later more because you wanted to?

**Donna:** Yes, yes.

**Interviewer:** So how do you define recovery?

**Donna:** Define recovery? I would read, I would read up on it like in the blue book that we have.

**Interviewer:** So learning more about it helps with recovery?

**Donna:** Yeah, but no one will talk about it. No one will talk about the grandiose thoughts in S.A. They won't talk about where they come from, the grandiose thoughts. My brother told my mom that he still had it once in a while. He's got a house and people would drive by and look in and look at the yard and he would go see how they look at my nice yard. But I think he thought for a while that they were looking at him you know and thinking.

**Interviewer:** Some of that paranoia?

**Donna:** Yeah. He told my mom that he still had some of it. But what was the question?

**Interviewer:** How do you define recovery? What does recovery look like for you?

**Donna:** Exercise, eating right, keeping taking the medicine, and if you've got these thoughts tell your doctor or your therapist. My therapist is fantastic. She said, "You're not special; you don't have any more powers than anybody else." She says, "These people aren't talking about you, you aren't special." I told her a long time ago that that's the worst that people had done to me I say I think I'm special and people said, "Well you are." And that's the worst because it props up those thoughts for me. It hurt me.

**Interviewer:** I bet you know some of those statements if it was someone you didn't trust you know saying you're not special, you wouldn't trust that.

**Donna:** Yes.

**Interviewer:** So it's good that you have a good relationship with your therapist?

**Donna:** Yeah it's fantastic. She'll say one word and I'm done. She'll say one sentence and I say, "Fine, fine."

**Interviewer:** So you kind of get on a roll and she says, "We're not doing that today."

**Donna:** Yeah, yeah. These grandiose, these grandiose thoughts, they ruined me. They almost killed me three times.

**Interviewer:** Were you doing something that you probably physically couldn't do?

**Donna:** I thought I hurt Jesus. I thought I had hurt Jesus three times.

**Interviewer:** Yeah I think sometimes people don't always realize the impact that that can have. People can look on the surface and go, "Oh you think you're great, that's fine," but you know if you think you're overly great that can get you into a lot of trouble.

**Donna:** Yeah it did get me into trouble. Because I would hear voices and I thought I was, I thought I had to die so that Jesus would be all right. Isn't that weird? It's weird. I cut my wrists once and then I took there was a storm and, let's see, I thought I had to die. The first time I cut my wrists I thought I had to die because it had to do with God. I wanted him to feel all right. And the second time a storm came when I was working outside of [Store] you know there used to be a [Store] in [City] and the sky was like the sky when I cut my wrists so I took an overdose.

**Interviewer:** So that was a big trigger?

**Donna:** Yeah, because of the sky. And then the last time that I tried to commit suicide it was a religion thing.

**Interviewer:** Yeah, I think you were talking about that last week, kind of getting too invested?

**Donna:** Yeah this guy kept praying, praying, praying, and I kept crying, crying, crying, and he said, “Jesus wants you to be his bride.” Can you imagine saying that to me? Gosh. He meant it as the church, you know, the church as the bride.

**Interviewer:** He meant it more like a metaphor and you were like, “I’m going to take this literally.”

**Donna:** Yes. I told him about it. I was like, “Why did you tell me that I was going to be the bride of Jesus?” And he goes, “Well I meant the church, the church is the bride of Jesus.” So anyway when he told me that I kept crying and I thought, well I should die so that Jesus could live. I thought I had hurt Jesus. I heard voices voices screaming and so I thought I should hurt myself. Yeah.

**Interviewer:** That’s pretty intense. So is recovery not having those thoughts? Or is it understanding what they mean or living with them and trying to ignore them?

**Donna:** No one will tell me what they really mean. So they say when you have those thoughts you have to talk to me. My therapist will tell me you have to tell me, and tell the doctor. I have an appointment with him practically every two weeks and I told him, I have to see him, I don’t know why I just have to see him. And that’s all I know. You know, I just.

**Interviewer:** It sounds like communicating with people you trust is a really big part of recovery?

**Donna:** Yeah and people I don’t trust very much, I try to trust. Yeah.

**Interviewer:** That can be hard.

**Donna:** Yeah that’s hard.

**Interviewer:** What role does medication play in your recovery?

**Donna:** Well if I didn’t take it, I would probably be dead. Yeah, I would be dead if I didn’t take it. Because I would think that the world revolved around me and that everything that any one said applies to me and everything and anything applied to me.

**Interviewer:** That sounds like an exhausting place to be.

**Donna:** Yeah. It’s very, you wouldn’t know it; you wouldn’t know how bad it is

**Interviewer:** But medication helps to keep that in check.

**Donna:** Yeah.

**Interviewer:** What has had the greatest impact on your recovery?

**Donna:** The greatest thing that helped me feel better? The greatest thing that helped me feel better was to know that I was a schizophrenic and to do something about it. So I did. I did something about it. My priest told me to get away from that doctor, that psychiatrist, he’s no good. So I went to the hospital and found a good doctor at a good hospital where there was a good doctor and then I ended up back here and I never felt better in my life when I came back here because the people up here are much more friendly than the people down there. The people up here are better. I don’t know why.

**Interviewer:** Well this is also where your family is?

**Donna:** Yeah my parents are here. Yeah they’re getting up there though, I’m scared.

**Interviewer:** So it sounds like the big impact for recovery was to know what was going wrong?

**Donna:** Yeah, what was wrong.

**Interviewer:** So once you labeled that, it was, there's these steps I can take to get back to feeling better?

**Donna:** Yeah, yeah.

**Interviewer:** Very cool.

**Donna:** But, you know, other people have it worse than I do. [Frank] has it all of the time. All of the time. I don't know about [Rebecca]. No one will open up at S.A. No one will open up. I don't know, people have it hard.

**Interviewer:** I think sometimes it's hard to open up because the meeting is only an hour long and then we've got to go.

**Donna:** Yeah.

**Interviewer:** So with some of that stuff it's hard to open up because then you have to close it back up really quick.

**Donna:** Yeah I like to talk, when [Carl] has a problem, I like to hear it.

**Interviewer:** Yeah a couple of weeks ago I know you really helped him.

**Donna:** Yeah, yeah.

**Interviewer:** I always really appreciate it when you put something out there and ask people to bring stuff forward.

**Donna:** Yeah I learned that at [H], it was a skill I learned at [H]. We had groups all the time. Group therapy all the time, and I brought up things that I never knew were possible. I brought out I helped people a lot I said this or that and I just helped them.

**Interviewer:** Do you think that helping others helps you?

**Donna:** Yes, when [Carl] said that to me last week he said, "Thanks a lot" for something I don't know what it was, I should have asked him, but I said, "Sure." You know it made me feel real good because I helped him. That way he opens up and that helps me to understand what's going on with me, what's going wrong with me, and that's how a lot of people don't have that.

**Interviewer:** So it sounds like finding people that you share experiences with has been really important to you.

**Donna:** Yeah, yeah. And [Frank], he won't, he won't learn. He doesn't learn for some reason. I don't know why, but he has it so bad that he can't hardly function. He's got it bad. I'm blessed right now. I've never had it better in my life than I do right now.

**Interviewer:** That's a nice place to be.

**Donna:** Yeah I've never had it any better. The place I live there's a lot of people that laugh at me. I'm practically the only white person there, not the only, but practically. I don't know maybe it's my imagination that they are laughing at me but my therapist said that it is, she said, "They don't laugh at you, there's nothing to laugh at you about."

**Interviewer:** That's true.

**Donna:** Yeah so I have a good place to live. I'm moving soon to a new place where there's not as many kids.

**Interviewer:** Yeah so it will be quieter?

**Donna:** Yeah I'm moving as soon as I turn 62.

**Interviewer:** So you're moving to a different sort of place.

**Donna:** Yeah don't tell anyone where I'm moving but it's called park manor. It's a really nice place.

**Interviewer:** Yeah that will be nice and quiet.

**Donna:** Yeah and the grocery store is right there. There's places to walk and exercise. Now I run into people and they go, "hehehe" and, you know, so I'm glad I'm moving. But I wish [Ethel] would open up and [Rebecca] and now [Frank] does but [L] she's just kind of laughs sometimes. She's still pretty sick, but she's got it bad, because she works.

**Interviewer:** It sounds like S.A. has been helpful for you in the past – coming to realize that this is your diagnosis, that type of thing, and it sounds like it's still helpful, but you wish that it was a little bit of a different experience?

**Donna:** Yeah, I can't get past Step One.

**Interviewer:** Which one is Step One again?

**Donna:** I surrender. I surrender. I still have the thoughts the grandiose thoughts so I haven't surrendered altogether.

**Interviewer:** Can you work on the other steps at the same time as Step One?

**Donna:** Yeah.

**Interviewer:** But that's kind of where you get stuck?

**Donna:** Yeah.

**Interviewer:** Well I really appreciated your presentation on Step Two the other week.

**Donna:** Oh good, thank you.

**Interviewer:** I like that you generated conversation and that people shared.

**Donna:** Thank you, yes. That's my doctor in me.

**Interviewer:** That's funny. When you spend a lot of time with a certain therapist or a certain doctor and you start talking like them.

**Donna:** Yes, yes, but it doesn't hurt.

**Interviewer:** Yeah it's a good thing. That's learning.

**Donna:** Yeah, I mean if somebody didn't like me saying something because it sounded like a doctor, they are just hurting themselves. That's it, I don't care.

**Interviewer:** So my last question is: what would be important for people without schizophrenia about living with schizophrenia?

**Donna:** Well, my mom pretty much knows, my parents pretty much know.

**Interviewer:** What do they know?

**Donna:** They know. Well one time, they were visiting my brother and I at [H] and my brother goes, "I thought I was God," and I go, "Well I thought I was God." And my mom goes, "I got to get out of here." And she knows. What was the question?

**Interviewer:** What would be important for people without schizophrenia to know about living with schizophrenia?

**Donna:** I would say I would know, I would know, but I don't know what other people would know.

**Interviewer:** What would you want clinicians to know, or other people in your life to know, about what it is like to live with schizophrenia?

**Donna:** I would say that I would apologize and say that I'm sorry I had this thought and I didn't mean to be rude to you but I had these thoughts.

**Interviewer:** It sounds like you want people to know you are coming from a positive place and that sometimes that message gets a little messed up.

**Donna:** Yeah, yeah. Because in talking to somebody and I'm having delusions then later I remember that I did it and I apologize and everything turns out okay.

**Interviewer:** So it sounds like you want people to be a little understanding?

**Donna:** Yeah and to accept my apology. That's the main thing – to accept my apology and to talk to them about what it is. You know with other schizophrenics, to talk about what it is I'm feeling and how I'm feeling and stuff like that. How I'm feeling and why I'm feeling that way.

**Interviewer:** It seems like there's also a need to be heard.

**Donna:** Yeah and I didn't have that when I came to S.A. the first time.

**Interviewer:** And probably not always in the hospital either?

**Donna:** No, no.

**Interviewer:** I think sometimes people don't listen because they feel like they don't have to.

**Donna:** Yeah, when I volunteer for my church I felt really normal about everything and being around normal people helps it helps a great deal. I volunteered for my church, but I'm not around them very much. But that was when I was going to [Catholic] Church, when they had festivals. One time, the last one, this girl kept taking the wheel when I wanted to, and she would turn it and I got mad because of that. And also, when I was standing there, and we didn't have any business, she would just start talking to somebody else and wouldn't even talk to me. So I just I said I'm leaving and I left I didn't mean to do it, but and they never asked me to volunteer again.

**Interviewer:** It sounds like that person wasn't being very helpful or understanding.

**Donna:** No, no. The first time, the girl was great, the first girl I worked with.

**Interviewer:** Well that's the end of my questions. Is there anything we didn't talk about today that you want to make sure we talk about?

**Donna:** I just want another schizophrenic to open up and share stuff.

**Interviewer:** Sometimes, for a lot of that stuff, you can only control what you do, and so you can be a good model for what you want others to do. It might take other people another 6 years to open up, but if that's what you want you have to keep modeling for people.

**Donna:** I don't think they understand Step One either.

**Interviewer:** Maybe you should volunteer to lead Step One.

**Donna:** Yeah, I will.

**Interviewer:** Well, I just really really appreciate you coming to meet with me today and I enjoyed our talk.

**Donna:** You're welcome.

(End of interview.)

#### **Volunteer 6: Eddie**

**Interviewer:** The next thing I have for you to fill out is the demographics form asking you for some general information.

**Eddie:** Okay. How many more interviews do you have?

**Interviewer:** I have one set up for next week and then I may need just one more.

**Eddie:** Oh, okay. Do you want my age?

**Interviewer:** Yeah, your age.

**Eddie:** Do you want M for male?

**Interviewer:** Yeah, that's fine.

**Eddie:** Relationship status?



**Interviewer:** Yeah, are you single? Married? Divorced? It's complicated?

**Eddie:** Oh, married. Highest level of education? College.

**Interviewer:** What's your degree in?

**Eddie:** Accounting. Things I don't want to do anymore. Family composition? Currently? I have a wife, and I have children but they aren't at home. No children at home.

**Interviewer:** How many kids do you have?

**Eddie:** Three kids. Three children. And I have grandchildren. Significant social support?

**Interviewer:** Do you have any friends that are important to you? Anything in the community that you go to that's important to you?

**Eddie:** Just church. And S.A. And no, no military. I'm Christian. I don't get mixed up with the Christian church though. I'm retired. Current diagnosis? I don't know. He hasn't told me.

**Interviewer:** Okay, well you can put that down.

**Eddie:** I'm going to see my doctor next week. I'll just put that down. I've been previously diagnosed at age 35. Let me get my information out. I think I was 35. I have that info in my bag. I don't think I have it on me. Here it is schizophrenia. I have other problems too that you probably don't want to know about.

**Interviewer:** Maybe I do.

**Eddie:** I have asthma.

**Interviewer:** Oh there's an area at the bottom that says 'other health concerns' where you could put that.

**Eddie:** Oh, okay. There's other things, too. Knees. And I'm taking medication for heart problems. Previous? No, I'm current schizophrenia. Here check that over.

**Interviewer:** Okay.

**Eddie:** I didn't want to spell everything out.

**Interviewer:** Yeah, that's okay.

**Eddie:** I'm not a good speller.

**Interviewer:** Me either, that's why I type everything out.

**Eddie:** I should do that. I have an electric typewriter.

**Interviewer:** I used that have one of those.

**Eddie:** I had a problem this week. We had to take my computer down in to get fixed. Okay, in '77 was when I was first diagnosed with schizophrenia.

**Interviewer:** When and how did you first get diagnosed?

**Eddie:** What?

**Interviewer:** My first question is when and how did you first know you had schizophrenia?

**Eddie:** Okay, in well, actually it was in '75.

**Interviewer:** Okay, so you were first diagnosed in '77.

**Eddie:** Yeah with schizophrenia. But I wasn't diagnosed in '75.

**Interviewer:** Is that when you first had problems?

**Eddie:** Yeah when my wife got pregnant. It was very confusing around then. And they were trying to clean up the credit unions. That was hard too. They didn't clean them up even with my recommendations. But I was traveling and I think I had mental problems then.

**Interviewer:** So you were traveling?

**Eddie:** And that was later.

**Interviewer:** So in 1975 that was when you first had problems?

**Eddie:** Yeah, yeah, that was when I was off work that was the first time for about a month or so. That's when I first went to my family doctor and he put me on Valium and that wasn't cutting it. So in '77 I was walking around the neighborhood trying to get into houses. I was barefoot in the nude. Oh, it was awful. It was lousy.

**Interviewer:** Sounds a little awkward.

**Eddie:** Oh, yeah, I was doing all kinds of things. I had mason in there too my father in law was a mason. My grandfather was a mason and I had uncles that were masons but they were dead and my father in law was dead too but I had many Masonic cards and books from West Virginia but we gave that to my neighbor because he was a mason.

**Interviewer:** So in 1977 that you were diagnosed. Were you hospitalized at that time?

**Eddie:** Yes, I was in the hospital.

**Interviewer:** For how long?

**Eddie:** For a long time. About a month or longer. That was at [hospital] and well let's see I was off work for the whole month, I don't know how long I would have to check my records.

**Interviewer:** Yeah, so you were off work for a while and in the hospital.

**Eddie:** And all this time I was just using my time that I had accumulated. And I think in '76 what happened in then, I finally got back to work. It was hard to get back to work, I cried. No, let's see that was in '75 when I cried and I went off Valium and he told me to get back on it. In '77 I was seeing a psychiatrist, psychologist, MD?

**Interviewer:** Yeah, a psychiatrist.

**Eddie:** Yeah, the family doctor recommended him. That was good.

**Interviewer:** Are you seeing that person still?

**Eddie:** No, he's passed away I think so that was a long time ago. He was in the papers once. He just listened. It was good. I have a copy of my records. I gave them to the next guy. I always keep records. And I think that was. I was thinking, his name was like my grandmothers, he was black, [M]. Dr. [M]. [C] was the first doctor. He was connected with the hospital over there. He connected me with some other doctors. A woman doctor, a MD from Yellow Springs and after she left the hospital she went to Yellow Springs. I never went there I got a new doctor. He was a student doctor working at the hospital but he was an MD so he could prescribe medications. This was when Reagan was president. He was this is when political aspects enters into it. Before '77 there was governor, no before Ford, there was Nixon in '77. And he was amazing and that could have all tied in with the Masonic lodges. And before him was Ford and Carter and he ran up the debt which put me in the hospital. That was very upsetting and when Reagan got into office that's when I retired. And then Bush.

**Interviewer:** How did you manage work? With mental health issues and going to the hospital, how did work work out?

**Eddie:** Well they had I had problems there. And I was accused of something I didn't do. It wasn't at work. It was something else. And I don't remember doing it. My wife said I probably forgot about it because of the medication and my mental status and putting it out of my mind but I don't think I did it because I don't remember.

**Interviewer:** What was it?

**Eddie:** It was a robbery. It was a robbery at a store. I was in a shopping center in [City]. I was working in [City] and I was walking around the store. And I don't remember doing it. I didn't have any extra money. I didn't have anything extra. And she was back home and the next day.

**Interviewer:** Did you get arrested?

**Eddie:** I didn't get arrested until a week after, the next week. It was around my honeymoon, not that my anniversary when I got arrested.

**Interviewer:** How was that?

**Eddie:** It wasn't fun. I was put in prison.

**Interviewer:** Oh my gosh.

**Eddie:** They said I was guilty because of witnesses. I was in the area and somebody took my picture and they recognized me and they said I looked a lot like Dave Thomas, the Wendy's guy.

**Interviewer:** So you got into some trouble. When was that?

**Eddie:** '89? I need to get my records. I could have been arrested before when they caught me in the nude but I got out of that. I went swimming in the nude before somewhere else. Not very many people know about that.

**Interviewer:** Anything, as was in the consent form, anything you share will be held confidential. It won't be connected to your name or identity.

**Eddie:** Yeah that has to be very confidential. Yeah because of my mental status I was able to get retirement from the state. I wouldn't be able to do that now.

**Interviewer:** So it happened after you retired?

**Eddie:** No it caused my retirement from the state. My retirement was in January 89. No it was [X], 1989. That was the day I was found guilty. Law day! I was trying to lay down the law with the credit unions but they wouldn't take heed and my grandmother, my parents died after that. My mother died in '88 and both my parents died in '88. My mother died in June and my dad died in October. And my brother is bipolar and my son is diabetic. He was infantile. He is in the Navy. He had four years in the navy in a submarine. That's hard being in the navy.

**Interviewer:** It's hard being in the service.

**Eddie:** Yeah it's worst in the Navy because you don't hear from them. His car got taken in.

**Interviewer:** What?

**Eddie:** Yeah it was in an apartment complex in the parking there and it was only good for six months and he had to renew it and the wife of the other fellow didn't renew it. But that was when Forrest Gump came out. They were calling him that, not Forrest but Bubba. That was the black guy.

**Interviewer:** My next question is what do you think about your diagnosis? Do you agree with your diagnosis?

**Eddie:** Yeah, yeah, now I've had different psychologists, people in your position, diagnose me as bipolar.

**Interviewer:** Did that make sense at all?

**Eddie:** Well it did because my brother was bipolar so they thought I was bipolar but I was going through some more situations. Because of another situation I can understand the schizophrenia.

**Interviewer:** So for you does it feel like the schizophrenia comes in like episodes or is it all of the time for you?

**Eddie:** I don't have any voices any more. In '77 I heard voices. People I used to work with I thought they were talking to me through the plane and I thought they were going to meet me at the house but they weren't hear so the voices were not there and this was before I met with the doctor and the pastor he was in on it too and we had another person at church who is bipolar so he knows my situation. He went to war with me at the court and his wife was there at his court on Monday, which is his day off, it was his free day.

**Interviewer:** It's good to have that support.

**Eddie:** Yes my brother came down to the court too but I don't think he came down to hear the final, I'm not sure. He was working at the time too. My parents were still living but they did not accept me. And my brother doesn't accept my diagnosis because of psychiatry they don't the church doesn't go along with, and my parents don't go with my diagnosis.

**Interviewer:** How did you friends and family react to your diagnosis then? You said that your parents...

**Eddie:** They don't know about it well some of my friends might know but only the S.A. people know. Well maybe some other friends know a friend here and there but he doesn't I think he knows I've been diagnoses but he doesn't know what I've been going through. It's really my wife that knows and has had to deal with it.

**Interviewer:** Right, she's the one who knows everything?

**Eddie:** Yeah, basically.

**Interviewer:** She's with you day-to-day right?

**Eddie:** Yeah yes and how much I don't get done around here.

**Interviewer:** You said that your parents didn't believe in your diagnosis?

**Eddie:** No, it's the psychiatrist aspect. They don't believe in psychiatry. Yeah it's the religious aspect. There are certain Christian beliefs that do not believe in psychiatry. Now my pastor does. He believes in psychiatry in fact I counseled with him for a while, for a short while. In fact I was supposed to counsel with him once but I couldn't get off of work to go up there because he was in Springfield and I was in Cincinnati and they were holding me down there with work.

**Interviewer:** So it's not like your family said, oh you have a mental illness, it was more like medications are not the way to treat this.

**Eddie:** Well they just don't understand psychiatry. And I can see the sinful nature that enters into it. And you know about the sinful nature. Even you have been taught about the sinful nature and you've known about the problems with sinful nature. And they said, it's all the sinful nature and it was a lot of it still is. I'm still a sinner. I've accepted Christ, I accepted him when I was ten-years old.

**Interviewer:** Yeah, but you continue to live in acceptance of Christ.

**Eddie:** Yeah I've accepted that and all the problems that come with it. I've had to deal with it and deal with psychiatrist. My brother is a psychiatrist, not the MD. He's the same position that you're going to be.

**Interviewer:** A psychologist?

**Eddie:** Yeah or he was. He retired. He lives in Illinois and he understands and my dad, he couldn't visit me in the hospital, if he had come down because of his attitude towards my illness. He would put me down. My dad put me down all my life.

**Interviewer:** Yeah that's hard.

**Eddie:** That's the problem there and with the psychiatry too and my brother has been diagnosed with bipolar too because of psychiatry. I don't know what my brother does, older brother, but he has problems too.

**Interviewer:** Was there ever a time, because of your family background and culture that says psychiatry is a bunch of hooley, was there...

**Eddie:** Yeah it's the sinful nature. It's still the sinful nature.

**Interviewer:** Was there ever a time that you didn't take medications because of that or you didn't do treatment?

**Eddie:** Yeah, I went off of medications once and ever since I've stayed on them.

**Interviewer:** Wow, only one time?

**Eddie:** Yeah well I've missed a day a few times.

**Interviewer:** Yeah that makes sense. That's surprising because a lot of people go off medications often so what made you continue to take medications?

**Eddie:** Because of my psychiatry, because of the schizophrenia and because of my wife saying that I better take it too. I just have to keep my pills up to date. I've gone off aspirin because I was bruising and I was on another medication and I noticed when I get shots in my knees for my joints it isn't doing much good for my problem. I'm losing...

**Interviewer:** Is it the cartilage that you're losing?

**Eddie:** No it's the fat. I'm not sure. Let me tell you what it is.

**Interviewer:** Okay.

**Eddie:** Let's see. It's all of the things I told you. I have it on the computer. I better get a new one. And cataract surgery. Heel spur. I have hearing loss too. I've had injections to both knees I think I've had my fourth. I had my last one I think I had my last one in December of last year I have to have another one. I thought I had what I'm diagnosed with. I can't it's let me ask my wife. Alice, what's my knee problem called? It's something with the tendons.

**[Abby]:** No I don't know what the technical term is it. They are just worn out.

**Interviewer:** Why do we need the scientific term for it when we can just say they are worn out?

**Eddie:** Okay, it's, I'll ask the doctor.

**Interviewer:** No worries. My next question going back to talking about schizophrenia is: how do you define recovery?

**Eddie:** How do I define recovery? Not hearing the voices. Not being in the hospital. And I'm not recovered because I still have to take the medication and as you get older that medication is supposed to still bother you but I'm taking a sleeping pill but now I'm sleeping too long and if I might try getting off it next week but my wife won't be here next week. She's going out to see my daughter. I'd like to go too.

**Interviewer:** So basically recovery is not hearing the voices, not going to the hospital, staying stable.

**Eddie:** Yes.

**Interviewer:** But you say that you're not recovered because you're still on medications?

**Eddie:** Yes, yes, it's still the sinful nature, too.

**Interviewer:** What role then does medication play in recovery at all, if at all?

**Eddie:** The role? Seeing the doctor? Not much. I don't see him often or for very long.

**Interviewer:** So you need to see the doctor for medications, but he's not very helpful otherwise?

**Eddie:** Yeah I go to my dentist, to my allergist every two weeks to get my shot, three shots, then I go to my psychiatrist next week. I don't have one like you to go do therapy with.

**Interviewer:** Have you ever had therapy before?

**Eddie:** Yeah only with the doctor and with the pastor but the pastor doesn't with him, I've had other doctors. I've had when I was retired from the state I saw a doctor then in [City]. I was seeing my family doctor then he practiced where I see my psychiatrist now. He probably went to another location because he does that. And I've been to a psychiatrist over in [City] at the [University] Hospital and he diagnosed me with schizophrenia and that was when I wasn't seeing a psychiatrist and that was a problem.

**Interviewer:** Because you weren't on medications?

**Eddie:** No. I was on medications but I got them from my family doctor. I did go to one like you, a PhD. in [Town] and he was a member of our church he taught Sunday school and I saw him and he helped me get through the court. He wrote a report a lengthy letter to the court and the family doctor did too and my brother did too with his psychologist background about the robbery. I don't think I did it because I didn't have any extra money. I just didn't have anything extra. I don't think I did it.

**Interviewer:** It's scary to be...

**Eddie:** (to his wife) Right? Right? You don't have to listen in. You were there. You went through it.

**[Abby]:** yeah I'm just listening in to see if there's anything I can fill in.

**Interviewer:** It has to be really scary to be in court and to be arrested and have all of these things happening when you have no recollection of the event.

**Eddie:** Yes, yes, that's the problem and I wasn't seen in glasses at that time.

**[Abby]:** Yeah you were just seeing the family doctor and psychologist. He was doing the counseling and that's when all that happened and one thing the court said was that he had to see a psychiatrist for medication for the rest of his life that was one of the stipulations for not having to serve any time.

**Interviewer:** Are you still under stipulations from the court at all?

**Eddie:** No, no, I haven't had it sealed. I could probably have that sealed. Though I don't think they do that anymore. I would have had to pay an attorney a lot of money.

**Interviewer:** So it sounds like you had a conditional release so you were incarcerated. Were you at a hospital at all?

**Eddie:** No, the state wouldn't take me because of my income.

**[Abby]:** Fortunately with the letters that his brother wrote and that the doctors wrote, and we had a lot of character references.

**Eddie:** From the church – the church members. So they know but they aren't there anymore.

**[Abby]:** The judge gave, let him plead no contest and the judge ruled, "I'll tell you what your sentence would be but based on the circumstance I'm going to not impose a sentence." He had five years probation.

**Eddie:** No, I had three years.

**[Abby]:** Three, okay?

**Eddie:** No, two years.

**[Abby]:** Yeah it's been so long ago, so he had probation and part of that is that he had to take medications and our doctor was in college in [City] at the time and whenever we went to go visit her we had to report it to the probation officer. But he said, "Go home and let your family take care of you."

**Interviewer:** That's good, because it could have been so much worse. It's good that you had that social support and people fighting for you.

**[Abby]:** Yeah, there were a lot of people who came from the church and a lot of people who came to the hearings and at the trial, whatever you want to call it. And his brothers were there so he saw all the support that he had.

**Eddie:** People at S.A. don't know this. I go back to '77 when I talk to them.

**Interviewer:** Okay. Confidentiality, I promise.

**Eddie:** But I was having psychotic problems then but I think it was having to do with my work.

**Interviewer:** Because of the extra stress?

**Eddie:** Yes, yes, I was traveling all the time. I was in [City] at the time I was staying down there I was away from home. It was too far.

**Interviewer:** I know with any kind of mental health diagnosis, you need stability and you need support. So when you do have to travel, it will throw you off.

**Eddie:** Yeah, she has to stay with me. I don't know what would happen without her. I'm a controller and she doesn't let me control.

**[Abby]:** Yeah, I have to keep you on your toes.

**Eddie:** I do that all of the time. It's terrible. I do that in public. It's terrible.

**[Abby]:** Yeah we were very fortunate with the courts. And the doctor wrote, he said, "If you put that man in jail he's going to go in a corner and lose contact with everybody. Do you really want to do that to this person?" So the judge could see that.

**Eddie:** And with my sinful nature, jail would not be a good place.

**[Abby]:** Just when he was in overnight they wouldn't let him take his meds and that was scary, too.

**Eddie:** Yeah I couldn't sleep that night. I lay down and she came and got me out.

**[Abby]:** My boss put up the bond for him. Because he was out of county we couldn't just do the ten per cent or whatever. So my boss put up the whole bill. We paid him back eventually but he footed the bill. But we got it back when he was released but if we hadn't had that kind of support too we would have had to mortgage our house to get him out and he couldn't stay in there.

**Eddie:** We still had a mortgage.

**Interviewer:** So you would've had to get a second one?

**[Abby]:** Yeah, we would have had to do that.

**Interviewer:** It's one of those things where you are really lucky that it worked out how it did, but you're unlucky that you got into that situation at all.

**Eddie:** Yeah and I got a job at Meals on Wheels after that. And did that for 14 years until they said that I couldn't have any more vacations. I didn't even tell the boss that I had problems she just said that I couldn't have any more vacations. And so I quit.

**[Abby]:** Yeah and he hurt his ankle a couple times, and workers comp, tripping over stuff.

**Eddie:** And I lost a couple cars.

**Interviewer:** Wait, you lost cars?

**[Abby]:** No, it was accidents. Only one was his fault, backing into him and passing on the right. But about six months before the incident happened with the arrest and all that the doctor said, we were talking about the stress and he asked him if he could hang in there for another five years until he could do a regular retirement and he said yes, but six months later...

**Eddie:** Yeah I couldn't do it.

**[Abby]:** This was before laptops and they were making him carry around a regular computer.

**Interviewer:** You had to have a giant computer?

**Eddie:** Yeah they gave us carts, but that didn't work at all either. I had to take it all over downtown [City] and I didn't even know how to use a printer. I couldn't use a printer.

**A:** Just with all that stress he couldn't.

**Interviewer:** With all of that change at work?

**Eddie:** I still can't do the accounting on the computer with the spreadsheets. I haven't learned that. My son wants me to take a course on that. It's too confusing and when you put your finger on there and it's all pulling it up and pushing it down. I haven't done that.

**Interviewer:** My dad is an accountant too and he still uses the old calculator with the paper tape, you know those?

**Eddie:** Yeah, he uses those. That's good.

**[Abby]:** But that was a good job to have at the time. It got him out of the house and meeting people because he loves spending time with people.

**Eddie:** Yeah but I had trouble getting up in the morning.

**[Abby]:** Yeah now he's even worse.

**Eddie:** Yeah I'm worse now I'm worse.

**[Abby]:** Yeah one of the reasons I don't want to retire is I don't want to deal with him sleeping all day.

**Eddie:** Yeah I would still be asleep but the dog wanted to go out.

**Interviewer:** Animals are really good for getting you up and getting you moving.

**Eddie:** I was still sleeping all the time on the weekends when I was working because I couldn't sleep during the week.

**Interviewer:** I have just two more questions. What has had the greatest impact in your recovery?

**Eddie:** I think staying with her. I believed it's been staying with you (to his wife). I do! It would be a horrible thing if she ever left me. It would be horrible. I know we are not going to live forever. I'm 70 and she's four years younger than me. It's going to get harder. And the dog. She was trouble when we got her as a puppy. I can't walk her because of my knees.

**A:** But look at that face, she's worth it.

**Interviewer:** How old is the dog?

**Eddie:** She's five. She's a year younger than Ilene.

**A:** We had a schnauzer before her. She was 15. We still have her ashes over there.

**Interviewer:** Yeah, I'd do that with my pets too.

**A:** Yeah it was a long time. We had forgotten how much work a puppy is. When we got the schnauzer all three kids were home and they'd help with the care so it was very different when you bring a puppy in here with us two old folks.



**Interviewer:** Yeah, it's like a newborn.

**Eddie:** We won't be able to get a puppy again.

**A:** If something happens to her, we would have to get an older dog

**Eddie:** The dog helps, too, because she does move me around. I have to take care of her. She's comfortable with my wife there.

**Interviewer:** My last question, what would be important for someone who doesn't have schizophrenia to know about what it's like to live with schizophrenia?

**Eddie:** You don't want that. Oh, to live with it? To get doctor's help. If I didn't have the doctors help I would be a problem. My doctor practices down at the state hospital, but he also has a private practice in [Suburb] and I see him there. He lives in [L] but comes up here to practice two days a week. Otherwise, he's working at the state hospital. He's with [CMHC] but now it's Wellness something. He's still there.

**Interviewer:** Well that's the last of my formal questions, is there anything we haven't talked about that you would like to talk about?

**Eddie:** No, you've heard more than others. No, you don't want to hear anything more. It's the old sinful nature.

**Interviewer:** Well, I appreciate everything you have shared with me today.

**Eddie:** It's quite a bit. She took a tape of it.

**Interviewer:** Yeah I can't write this fast. I have to transcribe stuff.

**Eddie:** How are you going to write it all down?

**Interviewer:** I have no idea.

**Eddie:** No, you can see what I've gone through. If I came to you as a counselor, you would have heard all that. All right. That's enough. It's 4:10.

**Interviewer:** Okay.

(End of interview.)

### **Volunteer 7: Carl**

**Carl:** ...Take acting class because I'm studying, I've found that for the first time I've been able to go to mixed martial arts three times within seven days.

**Interviewer:** Are your muscles aching? Are they mad at you?

**Carl:** A little but I'm taking it easy and if I feel I get pushed too hard that kills my motivation and they know this but I'm trying to go when I can. I'm going to try and go Saturday to the next class and also I'm going to try to make sure I practice at home. I have an interest in martial arts acting but I have to study it and know about it in order to that. It's also for defense and wisdom and knowledge.

**Interviewer:** Yeah, it comes with knowledge about your own body.

**Carl:** Yeah, when you do weight training it can take a toll on your body, too.

**Interviewer:** So this is the demographics form asking you for some overall information about you.

**Carl:** Family composition?

**Interviewer:** Yeah I phrased that weird, basically just put down who is in your family, who you consider to be family.

**Carl:** Just siblings?

**Interviewer:** Yeah and whoever you're living with now

**Carl:** I actually have three brothers and one sister they are all much older and live on their own.

**Interviewer:** So you're the youngest?

**Carl:** Yeah. So I have to put them down?

**Interviewer:** No you don't have to. Put down whomever you want. Awesome so any questions about any of that so far?

**Carl:** I don't think so.

**Interviewer:** All right we will now be moving into our interview portion. My first question is when and how did you know you had schizophrenia?

**Carl:** I was first diagnosed with the disease when I was about 16 and when I first heard those words I was really upset.

**Interviewer:** Did you first hear them when you were 16 or later?

**Carl:** I probably when I was about 16. I was angry because of the stigma or a lot of people think that's multiple personality because that's what Hollywood portrays of schizophrenia. So I thought I kind of got agitated because I thought I had multiple personalities but I knew that wasn't true.

**Interviewer:** So were you kind of confused about what the diagnosis even meant?

**Carl:** Yeah, sort of. But later I found out what the major symptoms are like thought distortion, false perceptions, hallucinations, delusions, seeing things that people don't see or hearing things that people don't hear, grandiose thinking that you're either superman or that you're nothing. And having ideas that don't make sense. And also thinking you can read people's minds or thinking you can read other people's minds and today I'm glad, when I was younger, when I first got diagnosed I had my family and I appreciate my family support because without them I would probably be in jail or be killed.

**Interviewer:** That's one of my other questions: how did your family and friends react to your diagnosis?

**Carl:** They reacted good. I'm not sure. As far as my immediate family, they did. When it all came out, my parents decided I needed to go see a psychiatrist because I was saying I wanted to hurt myself and I wish I were dead.

**Interviewer:** Was that when you were 16?

**Carl:** A little bit later, and a little bit before. I remember I was going to high school and I wasn't doing my homework I wasn't participating in class. I was completely withdrawn and not interested in anything and...

**Interviewer:** So did the people around you notice that and become concerned for you?

**Carl:** Yeah I know the teachers were and I think I was taking rejection kind of hard and I even had thoughts about plotting revenge on people at high school but I'm glad I didn't do that because I would have ended up in jail or some crazy place and anyways, there was a lot of pressure when I was at high school and symptoms started to show when I was in that school in my sophomore year. I was fine during my freshmen year but they came up and things just went down hill. And I was tell myself that I needed to step up to the plate because otherwise the teachers wouldn't let you back in and then I would really be in a pickle. And I think later somehow that I wasn't motivated, I just wanted to be a vegetable and watch TV all the time.

**Interviewer:** Sounds a lot like you had some depression symptoms in addition to anything else that was going on at the time, too?

**Carl:** Yeah, true, true. And later I've been hospitalized and on the psych wards at local hospitals several times and I think one time I got the electric thing, the shock therapy.

**Interviewer:** Do you not remember?**Carl:** I remember a little bit, I remember who my first psychiatrist was, he was a good guy.

**Interviewer:** So at 16, were you hospitalized then?

**Carl:** Yeah and there was this young lady that I knew from the school and I don't know what possessed me to do this, and even now when I think about it, it kind of makes me anxious as you now notice. I wanted to date her I wanted to be honest and something told me, "Don't do that." And I regret a little bit but one thing I've got to understand is that I've got to move on and I can't live in the past.

**Interviewer:** So it bothers you that you didn't go for it?

**Carl:** Yeah. And but today I'm glad I've got the support I need and I'm glad I'm encouraged to take my medicine because if I believe that I didn't need to take it, crazy things would happen.

**Interviewer:** How did you get to that point from when you first heard your diagnosis and feeling angry to now when you feel that you do need these medications? What was that process like?

**Carl:** I'm not sure. But because people have told me that I need to take my medicine and sometimes I've believed something different and there have been times when I've experienced trouble and been stressed out, mad, angry at the world and I think I'm just getting frustrated and frustrated and it could cause me to have a stroke, my blood pressure to rise or have a blood vessel rupture or give myself an ulcer but when I take the medicine whatever is causing that anxiety it just causes my body to calm down and then I know I'm safe because I'm not all tensed up or anything

**Interviewer:** So it sounds like it was a combination of people that you trusted, and probably some people that you didn't trust either telling you that you needed this or then also experiencing the difference for yourself?

**Carl:** Yeah that's true and I've heard stories about other people who don't take their medicine and end up back in the hospital. There was this one lady that I went to group with at [CMHC] and she said that she thought she didn't need to take her medicine and ended up back in the hospital and that's why she was back in the program but I probably one thing that I haven't done is journal and read the blue book, the Schizophrenics Anonymous blue book and do some other reading and just try to journal and try to follow a simple plan to keep myself in recovery.

**Interviewer:** I want to get to what you think about recovery and what it is, but first I want to ask, what do you think about your diagnosis? Do you agree with it? Do you not agree with it? Did you agree with it from the start or not always?

**Carl:** Both yes and no. I remember earlier in this week I was having some hard times accepting people's actions and I thought it was my fault but then someone told me that some of these things that I think is a part of my illness and that's the lady said that's why I'm supposed to take education but I thought about called CrisisCare but something told me, "you need to relax and as long as you're on your medicine, you'll be just fine. You get along with people well and you won't be anxious, you won't be frustrated, and you won't be jealous. At least you'll be able to have clear thinking. And you know you don't have to do crazy things." And so I'm kind of not angry with me yet because I think I

need to look at myself and see the symptoms that I'm having but I'm glad they are at a minimum.

**Interviewer:** So it sounds like for the most part you agree with your diagnosis now, it makes sense to you and can see the symptoms happening at time.

**Carl:** Yeah.

**Interviewer:** I'm wondering it sounds like it might also be very hard at moments that what you're thinking or feeling or experiencing is something that is a symptom of your illness, or is not a symptom. Is it hard to figure out where that line is?

**Carl:** Yeah, here's a story. I want to tell you a story about what happened yesterday. I get gas at the Swifty and as I'm driving up I realized that I have ten dollars in my pocket and that was supposed to be for gas and my gas gauge is getting closer to 'E' and so I turn around and actually I had a check for ten dollars and I was going to go put it into the one credit union but I decided to go to the other credit union and then something says and when I go to this one credit union well first something tells me to go back to this one credit union on [W] because it's not that far from the gas station but then I'm halfway to the one on BP in front of the grocery store and something says, when I pull up to the ATM it says, "out of service temporarily" and I say, "Praise, Jesus." and I started laughing and then a voice tells me to go to the other credit union I want you to go there and I was like, "why would you want me to go there?" the other one was much more convenient but this was like right across the street and something said you'll be glad, you'll be doing the right thing if you go to the other credit union. So when I get there I put in my card and remove it and it says insert the check and insert the envelope I stuck it in there and I realized at that moment that that was my illness that that wasn't God and so hopefully if I'm lucky that check will show up on my account. So I know that like in religion there comes this dark spirit that causes chaos and he can disguise himself as God and just like he, just like my illness can sometimes be a disguise.

**Interviewer:** Yeah that makes sense.

**Carl:** It can deceive you and it can pretend that this is God talking to you and it might tell you to do something crazy. And I know that one thing we were talking about last night at the prayer meeting at the bible study comes with trusting God you may sometimes believe that God is trying to tell you to do something and you have to trust him and but sometimes that's not true.

**Interviewer:** Well, yeah. That's a spot where it's really hard to figure out where you stand and coming back to your illness, there's something to do with having an inner monologue but that's very different from experiencing voices and it can be hard to tell the difference sometimes.

**Carl:** Right, right. I'm glad that I got my mom is a very big support so was my dad when he was here and she helps me get through and helps me get my basic needs met and I want to keep going for as long as I can as long as I have enough money to pay for gas and to take care of car maintenance and plus we moved recently and praise God for that and good food. And anyways, for a long time I was in disagreement with the disease and I felt like if I could just give enough and to keep myself busy and to work hard and to either get my black sash or compete in the Tour de France or something if I could then have by the time I'm done I would be too tired to have negative thoughts or to think about hurting someone or myself.

**Interviewer:** Just trying to exhaust your self. What changed?

**Carl:** I don't know I just feel like I need to understand that I'm not alone. There are many times when I feel like I'm the only one going through what I'm going through and that it's my fault. Sometimes I've had the suicidal thoughts but I know now that other people that have shared with me that I know it would be a very foolish idea to take my own life and I think I was talking to someone yesterday there is this one lady that I know she was talking about because her feet were hurting her so bad, she was going to cut them off. I think she had put that on the Internet, on Facebook, and she said that she regretted putting that on there.

**Interviewer:** Yeah, just like with suicide, that's a permanent solution to a temporary problem.

**Carl:** Yeah and anyways I was going to share myself that I had thoughts about suffering and then I could make all the suffering go away and I know that's not a good idea because God still has a mission for me and he wants me to have he's giving me gifts, talents, knowledge, and desire to go out there and help other people who are still suffering and I'm the only one who can bring them out of that suffering.

**Interviewer:** So finding out that you weren't alone, that you weren't the only person with similar problems and a similar diagnosis, helped pull you out of that angry space?

**Carl:** A little bit and pardon the expression but I'm thinking how to say this. But I'm not sure that some of my experiences as a child had something to do with my negative attitudes. I don't want to say anything inappropriate to you but I think when I was about seven or eight, when I lived in my neighborhood, I guess no big loss, but I think I just have to understand that my past has impacted my experiences and I think when I was at a babysitter's we she babysat me and my elder cousin and I think she was doing something to me and no one cared and I tried to protect myself and I was powerless and it's really upsetting and I'm thinking maybe that's why I've done some mean things, but I know that God is with me and with his help I have nothing to worry about. And I need to praise him and thank him for that.

**Interviewer:** You've had some bad experiences, as a kid, growing up, and that you think that has led to your mental health concerns?

**Carl:** Sometimes I know I know God is good and I know that I was also raised as a sheltered child and that if I had gone and shared and been open with people when I was at the hospital as a teenager for the first time I had a lady that I would have been able to talk to, but maybe I'm wrong, I don't know what would have happened. But if I had opened up and talked to this person, and started dating her, because the reason that she was there was because her stepfather said that she had a gun in her chest of drawers and she said that she was keeping it for a friend and maybe God maybe I am sort of thankful for what happened because I have issues about me that if something were to happen things could start spinning out of control very fast and I could have been worse off.

**Interviewer:** I bet at the time keeping quiet and keeping to yourself was one way of protecting yourself. I think sometimes when we look back at things that we should have done or could have done, we forget that at that moment we had to do what we did to save ourselves.

**Carl:** Yeah I thought I was going to be better off and safer if I did that. And I really worry about that. Sometimes when I ask people out on a date and they say no I really get affected. But one thing that people have tried to tell me is that don't worry about it, it's

not the end of the world. And I read a dating book one time that I checked out from this library that says you need to be happy on your own, you can't be codependent.

**Interviewer:** That idea that you have to love yourself before others will?

**Carl:** True and I'm trying to believe. I guess that one of the reasons that I have it so rough was that I was introduced to this Brooke Shields movie before I turned ten and I was introduced to some other stuff.

**Interviewer:** Stuff that you were too young for?

**Carl:** Exactly, and my mother tried to stop me. I'll tell you this I don't watch MTV anymore because I guess that's one of those negative things for me because it alters my mind. I remember this one man, this founder of MTV saying, "I'm not the boss of your 14 year old child, I own your 14 year old child." And I'm trying not to be so egoistic, because someone told me that as long as God loves me, that's the only thing that matters.

**Interviewer:** So how did you get involved in treatment? Was it against your will or ...

**Carl:** Sort of. But I am thankful that I'm getting treated for this.

**Interviewer:** So when you were 16 it was against your will, you were sent to the hospital but didn't want to go?

**Carl:** No. I think I agreed to go. To try it. To see what it was like. And I think another issue is that I'm jealous and there's some attractive young women who have mental illness as well and someone I have this crazy idea that I could ask them out and we could have a good time because we have something that we share but I know that that's not a good idea. And to tell you the truth, maybe God is telling me that I'm not ready for that relationship I'm kind of there are two young ladies that I want to ask out on a date and something told me to stop and something else told me that they are not interested. And that really bothered me. And but I am trying to be gracious and to do what I can to manage my symptoms and to try to stay busy and to try to plan my day. And one thing that I'm going to try to do is to do something creative and to get into art or to replace the drum set that was lost by my late father. And maybe practice some martial arts techniques and get good at it and do something drawing or something.

**Interviewer:** So that's part of treatment is keeping busy and getting creative. So that's stuff that you want to do in the future. What about how you ended up with your current treatment providers?

**Carl:** Well I was at the hospital after I turned 20. And that was definitely involuntary because I was so paranoid when I was at the medical center that I thought I was going to die that I was going to go hell just by these lights looking funny. It said emergency but there was black around the red letters and I kept fussing, I was trying to convince my mom to take me back home because I thought it said, "Welcome to hell." and I was like what is going on with that and anyways, all I had to do was sign myself in and go upstairs and everything would be fine and if I wanted to go home the next day, I could have and I was too scared, I was playing games, I know now not to do that.

**Interviewer:** But you had to learn the hard way?

**Carl:** Right. But I was in there for a month and after I came back here my psychiatrist asked me to do was go to [CMHC] because it's a good place so I took her suggestion and I was, I had my medical records transferred there and I've been there ever since.

**Interviewer:** So it started involuntary, with you going to the hospital and not wanting to be there and freaking out there and then it ended up being okay and you did what you had to do?

**Carl:** Yeah, and I'm glad. I was so nervous about that and I thought about maybe moving and having my services transferred but I'm at a good place and I think that if I wanted to participate in my treatment, it will go a whole lot smoother.

**Interviewer:** And they are a big place, with a lot of different kinds of services.

**Carl:** Yeah I have someone helping me find work, turning in applications and looking around and that's working out.

**Interviewer:** That's good. So how do you define recovery?

**Carl:** Just not being in relapse and being positive.

**Interviewer:** So does that mean being completely symptom free? Or having some symptoms but managing them?

**Carl:** So that my life is manageable and things are not out of control and I'm able to get through and not do anything crazy, not panicking, not calling the police all the time, or yelling at people.

**Interviewer:** Sounds like recovery is feeling that are more in control of your life?

**Carl:** Yeah with the help of my higher power and where I can still talk to people and keep up the day to day things that I have to do and not having to ask permission from anyone.

**Interviewer:** That's a good picture of recovery. I think that last piece is really comes from the hospital where you have to ask for permission for everything.

**Carl:** Yeah.

**Interviewer:** What role does medication play in your recovery?

**Carl:** Just as long as I take it I don't have to worry about going to the hospital and I take it because it does help and another thing I probably need to work on is figuring out how they work, how each drug is helping me and I know I need to take it in order to stay in recovery.

**Interviewer:** What are you on?

**Carl:** Zyprexa, lorazepam, effexor, invega, lamictal, luvox...

**Interviewer:** I've never heard of that one.

**Carl:** And cogentin. How many was that, seven?

**Interviewer:** I think it was seven. I've never heard of Luvox before, is that a new one?

**Carl:** Yeah I think it's an antidepressant and it helps. One time I think I was in the hospital and I think one drug that the doctor introduced was the lamictal and it helped.

**Interviewer:** Yeah that's an antidepressant and an anticonvulsant. So people who have seizures take that too.

**Carl:** Okay. That's a relief because sometimes when I might have trouble accepting the truth about something because if someone says something that I've never heard of before but something says, "You need to accept this, I know you don't like it but you need to accept it." Sometimes it's, I may be disappointed in what I hear because it's something that I don't want is someone to walk away. But I know that if I help myself, then I will be able to get what I need. I remember one time told me that God helps those that help themselves.

**Interviewer:** For me that comes back to recovery meaning that you have to take charge of your recovery. So instead of letting the doctors prescribe whatever, you saying this helps, this doesn't, I can't deal with this side effect, or this one is fine. So taking an active role is important?

**Carl:** Yeah, I remember, well I guess this isn't important, but there's a preacher at my church who doesn't have sympathy for those that refuse to work. But that's another thing.

**Interviewer:** Well, how do you define work? Because taking care of all of this stuff and managing your illness and managing all the appointments, and managing all those benefits and trying to keep busy and get through the day, that's a 60-hour work week.

**Carl:** True.

**Interviewer:** I think sometimes we need to expand our idea of the meaning of the word work.

**Carl:** Yeah I have an uncle. He's a minister. And he's a workaholic he told me that one time and I wanted to be like him. I'm sure it's because he has all these fancy cars and fancy clothes and that's he's walking with God and maybe I was a little jealous, but I thought that maybe if I could be a minister I would be happier or if I was a workaholic I could be happier, but I guess one thing that I need to understand is that I have to honor my parents for who they are and what they are teaching, because if God didn't think they were the right parents he wouldn't have given me them and I would have been adopted. I have to be thankful for them – it's one of the commandments and don't worry about what the preacher says or what the people in Sunday school say, just don't worry about them and take care of yourself and be at peace with yourself.

**Interviewer:** Which is harder than it sounds.

**Carl:** Right. So I need to listen to what God tells me and what my parents tell me and not what someone else tells me. People can give me advice and I can understand that and respect their opinion, but I need to honor my heavenly father and my father and my mother because they love me and care about me a whole lot and you know I know that if I put my faith in God, in my higher power, and try at least maybe most of the time to have faith in him that I'll be just fine.

**Interviewer:** What has had the greatest impact in your recovery?

**Carl:** Having a little faith. Reminding myself, making a vow that if I die it's going to be by God's hand not mine. What I mean is that I think S.A. has something to do with it as well.

**Interviewer:** The seventh step of "I choose to live"?

**Carl:** Yeah and I think all the seven steps have to do with it. And I think the people at S.A. have a lot in common with some of the members and that's a relief to me because they understand where I'm coming from and I understand where they are coming from and I have some of the same experiences and I feel relieved by that.

**Interviewer:** So feeling less alone and having faith are the big things for recovery?

**Carl:** I think so yeah. And just having counseling and going to [CMHC].

**Interviewer:** Engaging in treatment?

**Carl:** Right.

**Interviewer:** So my last question is: what would be important for people without schizophrenia to know about what it is like to live with schizophrenia?

**Carl:** I'm not sure that I have an answer to that question. But one good idea to share with others about what it's like to have schizophrenia?

**Interviewer:** What do you want people to know?

**Carl:** That it's a disease that's like any other disease and that it needs to be treated and there are all kinds of people who have it if you see someone acting weird don't take it as



some one is committing a crime or acting antisocial, but maybe they are doing something that's beyond their control. Well, let me, I'm not sure about this. I want to say that it's a disease and with the proper treatment, it can be manageable and that they can be happy and healthy as long as they take their medicine and do the things that they were taught and participate in their recovery and that they are normal just like anyone else.

**Interviewer:** It sounds like you just want some understanding. Sometimes people make really negative assumptions about people with schizophrenia and that you want people to know that those are unfair?

**Carl:** Right. And I hope that the county court system can understand that. I think I voted for someone because she understands people who are mentally ill and that she upholds the law. And I was afraid that people would maybe doing things that are out of control because they are off their medicine would go to jail instead of the hospital and I know in my case, people often make the assumption or judgment about how I'm doing and I wouldn't be thinking about that and it would make me feel pretty worthless and in the past it would make me think about suicide but not anymore because I remain, because God loves me and there are lots of other people who care about me and they would be upset.

**Interviewer:** You would be leaving a lot of people behind.

**Carl:** True.

**Interviewer:** I like that you talked about voting for someone because they had mental health awareness as part of their platform and that's a part of advocacy and action.

**Carl:** Right, right. And I can't remember what I wanted to tell you. I may be, it's God's will for me to help others who are still suffering and I thought about doing one class at the Castle that I would have to prepare for and if I want people to listen to me then I'm going to have to prepare and work at it. And I would like to open my own bakery or my own restaurant, pizzeria. But I'm not sure what God wants me to do with the rest of my life. He may want me to be some kind of leader since he's brought me out and in recovery. And there are times where I've done presentations and I've led the class at S.A. and I could have done a better job. I should have worked at it harder, at least two hours each day working hard preparing for that. To be prepared for that presentation.

**Interviewer:** That's a lot and would be hard to do.

**Carl:** Yeah, you're right. But I think I would like to be in ministry too. Last night we were talking about that and we have a newer audience and kind of having an idea about what they need to hear in order to give them hope even though they might have to do something they are uncomfortable with.

**Interviewer:** Well that's it for my questions. Is there anything that we didn't talk about today that you would like to talk about?

**Carl:** I think I'm good. And I think I'm going to try to worry about connecting more with people at S.A. and I'm going to work harder to stay in recovery.

**Interviewer:** Well, I so appreciate you meeting with me today and I enjoyed our conversation.

**Carl:** Okay.

**Interviewer:** Thank you.

(End of interview.)

## References

- Abdel-Baki, A., Ouellet-Plamondon, C., & Malla, A. (2012). Pharmacotherapy challenges in patients with first-episode psychosis. *Journal of Affective Disorders*, 138, S3-S14.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (Revised 4<sup>th</sup> ed.). Washington, DC: Author.
- Andresen, R., Caputi, P., & Oades, L. G. (2010). Do clinical outcome measures assess consumer-defined recovery? *Psychiatry Research*, 177, 309-317. doi: 10.1016/j.psychres.2010.02.013
- Andresen, R., Oades, L., & Caputi, P. (2003). The experience of recovery from schizophrenia: Towards an empirically validated stage model. *Australian and New Zealand Journal of Psychiatry*, 37, 586-594.
- Appleby, L., Mortensen, P. B., Dunn, G., & Hiroeh, U. (2001). Death by homicide, suicide, and other unnatural causes in people with mental illness: A population-based study. *The Lancet*, 358(9299), 2110-2112.
- Auerback, C. F., & Silverstein, L. B. (2003). *Qualitative data: An introduction to coding and analysis*. New York, NY: New York University Press.
- Bassman, R. (2005). Mental illness and the freedom to refuse treatment: Privilege or right. *Professional Psychology: Research and Practice*, 36(5), 488-497. doi: 10.1037/0735-7028.36.5.488
- Bassman, R. (2001). Whose reality is it anyway? Consumers/survivors/ex-patients can

- speak for themselves. *Journal of Humanistic Psychology*, 41(4), 11-35.
- Bassman, R. (2000). Agents, not objects: Our fights to be. *JCLP/In Session: Psychotherapy in Practice*, 56(11), 1395-1411.
- Bassman, R. (1997). The mental health system: Experienced from both sides of the locked doors. *Professional Psychology: Research and Practice*, 28(3), 238-242.
- Beeble, M. L. & Salem, D. A. (2009). Understanding the phases of recovery from serious mental illness: The roles of referent and expert power in a mutual-help setting. *Journal of Community Psychology*, 37(2), 249-267.
- Botha, U. A., Koen, L., Joska, J. A., Parker, J. S., Horn, N., Hering, L. M., & Oosthuizen, P. P. (2010). The revolving door phenomenon in psychiatry: Comparing low-frequency and high-frequency users of psychiatric inpatient services in a developing country. *Social Psychiatry Epidemiologist*, 45, 461-468. doi: 10.1007/s00127-009-0085-6
- Borg, M., & Davidson, L. (2008). The nature of recovery as lived in everyday experience. *Journal of Mental Health*, 17(2), 129-140. doi: 10.1080/09638230701498382
- Braddock, D. L. & Parish, S. L. (2001). An institutional history of disability. In G. L. Albrecht, K. D. Seelman, & M. Bury (Eds.). *Handbook of disability studies*. Thousand Oaks, CA: Sage.
- Chadda, R. K., Agarwal, V., Singh, M. C., & Raheja, D. (2001). Help seeking behavior of psychiatric patients before seeking care at a mental hospital. *International Journal of Social Psychiatry*, 47(4), 71-78.

- Cohen, C. I., Jiminez, C., Mittal, S. (2010). The role of religion in the well-being of older adults with schizophrenia. *Psychiatric Services*, 61(9), 917-922.
- Cook, J. A., Shore, S. E., Burke-Miller, J. K., Jonikas, J. A., Ferrara, M., Colegrove, S., Norris, W. T., Ruckdeschel, B., Batteiger, A. P., Ohrtman, M., Grey, D. D., & Hicks, M. E. (2010). Participatory action research to establish self-directed care for mental health recovery in Texas. *Psychiatric Rehabilitation Journal*, 34(2), 137-144.
- Cummings, S. M. & Kropf, N. P. (2009). Formal and informal support for older adults with severe mental illness. *Aging and Mental Health*, 13(4), 619-627.
- Cummings, S. M. & Kropf, N. P. (2011). Aging with a severe mental illness: Challenges and treatments. *Journal of Gerontological Social Work*, 54(2), 175-188.
- Davidson, L. (2010). PORT through a recovery lens. *Schizophrenia Bulletin*, 36(1), 107-108. doi: 10.1093/schbul/sbp138
- Davidson, L., Chinman, M., Kloos, B., Weingarten, R., Stayner, D., & Tebes, J. K. (1999). Peer support among individuals with severe mental illness: A review of the evidence. *Clinical Psychology: Science and Practice*, 6(2), 165-187.
- Davidson, L., O'Connell, M. J., Tondora, J., Lawless, M., & Evans, A. C. (2005). Recovery in serious mental illness: A new wine or just a new bottle? *Professional Psychology: Research and Practice*, 36(5), 480-487. doi: 10.1037/0735-7028.36.5.480
- Dickerson, F. B., Lehman, A. F. (2011). Evidence-based psychotherapy for schizophrenia: 2011 update. *Journal of Nervous and Mental Disease*, 199(8), 520-526.

- Fenton, W. S., & Schooler, N. R. (2000). Editor's introduction: Evidence-based psychosocial treatment for schizophrenia. *Schizophrenia Bulletin*, 26(1), 1-3.
- Fitzgerald, M. M. (2010). Comparison of recovery style and insight of patients with severe mental illness in secure services with those in community services. *Journal of Psychiatric and Mental Health Nursing*, 17, 229-235.
- Gelman, S. (1999). *Medicating schizophrenia: A history*. New Brunswick, NJ: Rutgers University Press.
- Gelo, O., Braakmann, D., & Benetka, G. (2008). Quantitative and qualitative research: Beyond the debate. *Integrative Psychological and Behavioral Science*, 42, 266-290. doi: 10.1007/s12124-008-9078-3
- Gill, C. J. (1997). Four types of integration in disability identity development. *Journal of Vocational Rehabilitation*, 9, 39-46.
- Gioia, D. (2005). Career development in schizophrenia: A heuristic framework. *Community Mental Health Journal*, 41(3), 307-325. DOI: 10.1007/s10597-005-5004-z
- Gray, R., Bressington, D., Lathlean, J., & Mills, A. (2008). Relationship between adherence, symptoms, treatment attitudes, satisfaction, and side effects in prisoners taking antipsychotic medication. *The Journal of Forensic Psychiatry and Psychology*, 19(3), 335-351.
- Gulliver, A., Griffiths, K. M., & Christensen, H. (2010). Perceived barriers and facilitator to mental health help-seeking in young people: A systematic review. *BMC Psychiatry*, 10, 113. Retrieved from <http://www.biomedcentral.com/1471-244X/10/113>

- Heinrichs, R. W., Ammari, N., McDermin Vaz, S., & Miles, A. A. (2008). Are schizophrenia and schizoaffective disorder neuropsychologically distinguishable? *Schizophrenia Research*, 99, 149-154.
- Hendryx, M., Green, C. A., & Perrin, N. A. (2009). Social support, activities, and recovery from serious mental illness: STARS study findings. *Journal of Behavioral Health Services and Research*, 36(3), 320-329.
- Huang, C. L., Shang, C., Shieh, M., Lin, H., & Su, J. C. (2011). The interactions between religion, religiosity, religious delusion/hallucination, and treatment-seeking behavior among schizophrenic patients in Taiwan. *Psychiatry Research*, 187, 347-353.
- Inder, M. L., Crowe, M. T., Moor, S., Luty, S. E., Carter, J. D., & Joyce, P.R. (2008). "I actually don't know who I am": The impact of bipolar disorder on the development of self. *Psychiatry*, 71(2), 123-133.
- Insel, T. (2011, August 12). Mental illness defined as disruption in neural circuits. Retrieved from <http://www.nimh.nih.gov/about/director/index.shtml>
- Insel, T. (2010, November 10). From cognition to genomics: Progress in schizophrenia research. Retrieved from <http://www.nimh.nih.gov/about/director/2010/from-cognition-to-genomics-progress-in-schizophrenia-research.shtml>
- Keller, W. R., Fischer, B. A., & Carpenter, Jr., W. T. (2011). Revisiting the diagnosis of schizophrenia: Where have we been and where are we going? *CNS Neuroscience and Therapeutics*, 17, 83-88.
- Kidd, S. A., & Kral, M. J. (2005). Practicing participatory action research. *Journal of Counseling Psychology*, 52, 187-195. doi: 10.1037/0022-0167.52.2.187

- Kreyenbuhl, J., Buchanan, R. W., Dickerson, F. B., & Dixon, L. B. (2010). The schizophrenia patient outcomes research team (PORT): Updated treatment recommendation 2009. *Schizophrenia Bulletin*, 36(1), 94-103. doi: 10.1093/schbul/sbp130
- Landsman, G. (2005). Mothers and models of disability. *Journal of Medical Humanities*, 26(2/3), 121-139. doi: 10.1007/s10912-005-2914-2
- Leisey, M. (2008). Qualitative inquiry and the IRB: Protection at all costs? *Qualitative Social Work*, 7(4), 415-426.
- Levin, T. T. (2009). Letter to the editors: Newer conceptualizations of schizophrenia demand a name change. *Schizophrenia Research*, 115, 374. doi: 10.1016/j.schres.2009.09.013
- Lucksted, A., & Coursey, R. D. (1995). Consumer perceptions of pressure and force in psychiatric treatments. *Psychiatric Services*, 46(2), 146-152.
- Lynch, D., Laws, K. R., & McKenna, P. J. (2010). Cognitive behavioural therapy for major psychiatric disorder: Does it really work? A meta-analytical review of well-controlled trials. *Psychological Medicine*, 40, 9-24. doi: 10.1017/S003329170900590X
- Lysaker, P. H., & Buck, K. D. (2008). Is recovery from schizophrenia possible? An overview of concepts, evidence, and clinical implications. *Primary Psychiatry*, 15(6), 60-65.
- Lysaker, P. H., Roe, D., & Buck, K. D. (2010). Recovery and wellness amidst schizophrenia: Definitions, evidence, and the implications for clinical practice. *Journal of the American Psychiatric Nurses Association*, 16(1), 36-42. doi:

10.1177/1078390309353943

Mackelprang, R. W., & Salsgiver, R. O. (1996). People with disabilities and social work:

Historical and contemporary issues. *Social Work, 41*(1), 7-14.

Magliano, L., Fiorillo, A., Malangone, C., Del Vecchio, H., & Maj, M. (2008). Views of persons with schizophrenia on their own disorder: An Italian participatory study.

*Psychiatric Services, 59*(7), 795-799. doi: 10.1176/appi.ps.59.7.795

Martin, J. K., Pescosolido, B. A., & Tuch, S. A. (2000). Labels, and causal attributions in shaping public attitudes toward people with mental illness. *Journal of Health and Social Behavior, 41*, 208-223.

Mashiach-Eizenberg, M., Hasson-Ohayon, I., Yanos, P. T., Lysaker, P. H., & Roe, D.

(2013, April 6). Internalized stigma and quality of life among persons with severe mental illness: The mediating roles of self-esteem and hope. *Psychiatry Research*.

McGuire, P. A. (2000). New hope for people with schizophrenia. *Monitor, 31*(2).

Retrieved from <http://www.apa.org/monitor/feb00/schizophrenia.aspx>

Mohr, S., Borrás, L., Nolan, J., Gillieron, C., Brandt, P., Eytan, A., Leclerc, C., Perroud, N., Whetten, K., Pieper, C., Koenig, H. G., Huguelet, P. (2012). Spirituality and religion in outpatients with schizophrenia: A multi-site comparative study of Switzerland, Canada, and the United States. *International Journal of Psychiatry in Medicine, 44*(1), 29-52.

National Alliance on Mental Health (NAMI). (n.d.) What is schizophrenia? Retrieved from [www.nami.org](http://www.nami.org)

National Household Survey on Drug Abuse (NHSDA). (2002, October 18). Serious mental illness among adults. *The NHSDA Report*. Retrieved from



<http://oas.samhsa.gov/2k2/SMI/SMI.htm>

National Institute of Mental Health (NIMH). (2010, July 29). Annual total direct and indirect costs of serious mental illness (2002). Retrieved from

[http://www.nimh.nih.gov/statistics/4COST\\_TOTAN.shtml](http://www.nimh.nih.gov/statistics/4COST_TOTAN.shtml)

Neff, C. L. (1995). The bag lady's reality. *Psychiatric Services*, 46(4), 337-338.

Nolan, J. A., McEvoy, J. P., Koenig, H. G., Hooten, E. G., Whetten, K., & Pieper, C. F. (2012). Religious coping and quality of life among individuals living with schizophrenia. *Psychiatric Services*, 63(10), 1051-1054.

Olkin, R. (2002). Could you hold the door for me? Including disability in diversity. *Cultural Diversity and Ethnic Minority Psychology*, 8(2), 130-137. doi: 10.1037//1099-9809.8.2.130

Onken, S. J. & Slaten, E. (2000). Disability identity formation and affirmation: The experiences of persons with severe mental illness. *Sociological Practice: A Journal of Clinical and Applied Sociology*, 2(2), 99-111.

Padron, J. M. (2006). Experience with post-secondary education for individuals with severe mental illness. *Psychiatric Rehabilitation Journal*, 30(2), 147-149.

Pandya, A., Bresee, C., Duckworth, K., Gay, K., & Fitzpatrick, M. (2011). Perceived impact of the disclosure of a schizophrenia diagnosis. *Community Mental Health Journal*, 47, 613-621.

Perese, E. F. (2007). Stigma, poverty, and victimization: Roadblocks to recovery for individuals with severe mental illness. *Journal of the American Psychiatric Nurses Association*, 13(5), 285-295. doi: 10.1177/1078390307307830

Pescosolido, B. A., Martin, J. K., Long, J. S., Medina, T. R., Phelan, J. C., & Link, B. G.

- (2010). "A disease like any other"? A decade of change in public reactions to schizophrenia, depression, and alcohol dependence. *American Journal of Psychiatry*, 16(7), 1321-1330.
- Pledger, C. (2003). A new model of disability: Discourse on disability and rehabilitation issues: Opportunities for psychology. *American Psychologist*, 58(4), 279-284. doi: 10.1037/0003-066X.58.5.279
- Ponterotto, J. G. (2010). Qualitative research in multicultural psychology: Philosophical underpinnings, popular approaches, and ethical considerations. *Cultural Diversity and Ethnic Minority Psychology*, 16(4), 581-589. doi: 10.1037/a0012051
- Resnick, S. G., Fontana, A., Lehman, A. F., & Rosenheck, R. A. (2005). An empirical conceptualization of the recovery orientation. *Schizophrenia Research*, 75, 119-128. doi: 10.1016/j.schres.2004.05.009
- Reynolds, A. L. & Pope, R. L. (1991). The complexities of diversity: Exploring multiple oppressions. *Journal of Counseling and Development*, 70, 174-180.
- Ritsher, J. B., Otilingam, P. G., & Grajales, M. (2003). Internalized stigma of mental illness: Psychometric properties of a new measure. *Psychiatry Research*, 121, 31-49. doi: 10.1016/j.psychres.2003.08.008
- Ritsher, J. B., & Phelan, J. C. (2004). Internalized stigma predicts erosion of morale among psychiatric outpatients. *Psychiatry Research*, 129, 257-265. doi: 10.1016/j.psychres.2004.0.003
- Rowe, J. (2012). Great expectations: A systematic review of the literature on the role of family carers in severe mental illness, and their relationships and engagement with professionals. *Journal of Psychiatric and Mental Health Nursing*, 19, 70-82.

- Rudge, T., & Morse, K. (2001). Re-awakenings?: A discourse analysis of the recovery from schizophrenia after medication change. *Australian and New Zealand Journal of Mental Health Nursing, 10*, 66-76.
- Salem, D. A., Reischl, T. M., & Randall, K. W. (2008). The effect of professional partnership on the development of a mutual-help organization. *American Journal of Community Psychology, 52*, 179-191.
- Schizophrenia and Related Disorders Alliance of America. (2010). *Schizophrenics anonymous: Self-help peer support group: You are not alone: For those diagnosed with schizophrenia and related disorders*. Houston, TX: Author.
- Schizophrenia and Related Disorders Alliance of America. (2008, November 27). What is schizophrenics anonymous? Retrieved from [http://www.sardaa.org/what\\_is\\_SA.html](http://www.sardaa.org/what_is_SA.html)
- Shea, J. M. (2009). Coming back normal: The process of self-recovery in those with schizophrenia. *Journal of the American Psychiatric Nurses Association, 16*(1), 43-51. doi: 10.1177/1078390309359197
- Shean, G. D. (2009). Evidence-based psychosocial practices and recovery from schizophrenia. *Psychiatry, 72*(4), 307-320.
- Smart Ass Cripple (2011, February 2011). The super terrifying grandma Vanelli. Retrieved from <http://smartasscripple.blogspot.com/2011/02/super-terrifying-grandma-vanelli.html>
- Smith, L., Bratini, L., Chambers, D., Jensen, R. V., & Romero, L. (2010). Between idealism and reality: Meeting the challenges of participatory action research. *Action Research, 8*(4), 407-425. doi: 10.1177/1476750310366043

- Smith, L., Rosenzweig, L., & Schmidt, M. (2010). Best practices in the reporting of participatory action research: Embracing both the forest and the trees. *The Counseling Psychologist*, 38(8), 1115-1138. doi: 10.1177/0011000010376416
- Smith, S. & Suto, M. J. (2012). Religious and/or spiritual practices: Extending spiritual freedom to people with schizophrenia. *Canadian Journal of Occupational Therapy*, 79(2), 77-85.
- Spaniol, L., Gagne, C., & Koehler, M. (1999). Recovery from serious mental illness: What it is and how to support people in their recovery. In R. P. Martinelli & A. E. dell Orto (Eds). *The Psychological and Social Impact of Disability*. New York: Springer Publishing Company, Inc.
- Substance Abuse and Mental Health Services Administration (SAMHSA). (2008, September 24). Understanding Mental Illness: Factsheet. Retrieved from [http://www.samhsa.gov/mentalhealth/understanding\\_MentalIllness\\_Factsheet.aspx](http://www.samhsa.gov/mentalhealth/understanding_MentalIllness_Factsheet.aspx)
- Sue, D. W., & Capodilupo, C. M. (2008). Racial, gender, and sexual orientation microaggressions: Implications for counseling and psychotherapy. In D. Sue, & S. Sue (Eds.). *Counseling the culturally diverse* (5<sup>th</sup> ed.) Hoboken, NJ: John Wiley & Sons.
- Tate, D. G., & Pledger, C. (2003). An integrative conceptual framework of disability: New directions for research. *American Psychologist*, 58(4), 289-295. doi: 10.1037/0003-066X.58.4.289
- The Internet Mental Health Initiative (n.d.). Schizophrenia Facts and Statistics. Retrieved from <http://www.schizophrenia.com/szfacts>
- Tsai, J., Desai, R. A., & Rosenheck, R. A. (2011). Social integration of people with

- severe mental illness: Relationships between symptom severity, professional assistance, and natural support. *Journal of Behavioral Health Services and Research*, 39(2), 144-157
- Tsai, J. & Rosenheck, R. A. (2012). Conceptualizing social integration among formerly homeless adults with severe mental illness. *Journal of Community Psychology*, 40(4), 456-467.
- U.S. Department of Health and Human Services. (1999). *Mental Health: A Report of the Surgeon General*. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health.
- Van Dongen, C. J. (2009). Self-esteem among persons with severe mental illness. *Issues in Mental Health Nursing*, 19, 29-40.
- van Zelst, C. (2009). Stigmatization as an environmental risk in schizophrenia: A user perspective. *Schizophrenia Bulletin*, 35(2), 293-296. doi: 10.1093/schbul/sbn184
- Villares, C. C., & Sartorius, N. (2003). Challenging the stigma of schizophrenia. *Review Brasilia Psiquiatri*, 25(1), 1-2.
- Walsh, J. (1994). Schizophrenics anonymous: The Franklin County, Ohio experience. *Psychosocial Rehabilitation Journal*, 18(1), 61-74.
- Wisdom, J. P., Bruce, K., Saedi, G. A., Weis, T., & Green, C. A. (2008). ‘Stealing me from myself’: Identity and recovery in personal accounts of mental illness. *Australian and New Zealand Journal of Psychiatry*, 42, 489-495.
- Wright, L. (2011, February 14). The apostate: Paul Haggis vs. the Church of Scientology. *The New Yorker*. Retrieved April 28, 2013 from

[http://www.newyorker.com/reporting/2011/02/14/110214fa\\_fact\\_wright](http://www.newyorker.com/reporting/2011/02/14/110214fa_fact_wright)

Yanos, P. T., Roe, D., Markus, K., & Lysaker, P. H. (2008). Pathways between internalized stigma and outcomes related to recovery in schizophrenia spectrum disorders. *Psychiatric Services*, 59(12), 1437-1442.

Yanos, P. T., Roe, D., & Lysaker, P. H. (2010). The impact of illness identity on recovery from severe mental illness. *American Journal of Psychiatric Rehabilitation*, 13, 73-93. doi: 10.1080/15487761003756860